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ABSTRACT

Following a description of the proceedings of the conference (including sponsors and a 3-day program), 12 papers are presented on the communication problems of the mentally handicapped. The keynote address, by S. Segal, reviews trends in teaching communication to mentally retarded persons, including the impact on teaching of British legislation and of computer technology. Subsequent papers include the following: "Communication between Agencies" (D. Leighton); "Improving Communication between the Caring Professions" (G. Carroll); "Towards a More Effective and Integrated Service" (A. Davison); "Makaton in the 1980's" (M. Walker); "The Development of Communcation Skills: Where Should We Go Next?" (C. Kiernan); "Communication Difficulties and Visually Handicapped People" (D. Ellis); "Educating Multiply Handicapped Children with Severe Behavioral Problems" (M. Jones); "A Computer Aided Implementation of Precision Teaching" (D. Lyons); "Overcoming Problems Facing Parents and Relatives" (T. Greaves); "Is That All Right for You?" (W. Apps); and "A Parent's Story" (M. Collins). Appendixes list the Makaton Vocabulary, and chart and list the organization for the Makaton Vocabulary Development Project. (CL)

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University of Essex

Department of
Language and Linguistics

Occasional Papers

Communication Problems of the Mentally Handicapped

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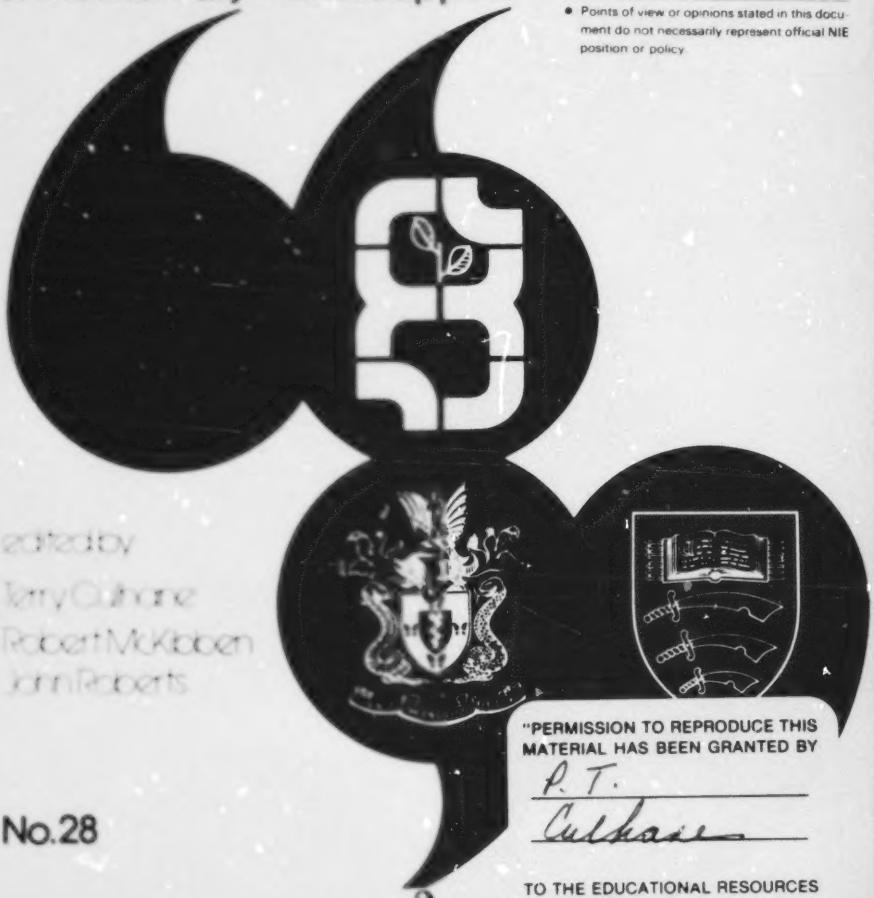

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John Roberts

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Occasional Papers

28: Communication Problems of the Mentally Handicapped

edited by P.T. Culhane, R. McKibben and J.T. Roberts

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COMMUNICATION PROBLEMS OF THE MENTALLY HANDICAPPED

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FOREWORD

I am delighted that the Project Horizon Conference took place at the University of Essex. This is partly because members of the University are involved in the activities of Project Horizon but it is also because the University shares the project's aims: perception, research, communication and education. We are both concerned with communication in its fullest sense, understanding not just the point of view of another person but also his needs and aspirations.

I hope that this Conference will be the first of many held at the University.

Dr A E Sloman
Vice-Chancellor
University of Essex

30.1.84

INTRODUCTION

Project Horizon was initiated in 1975 with the blessing of the then District Management Team and the then Essex Area Health Authority. The purpose was to establish links between the hospital and the town since Turner Village, like all Mental Handicap hospitals, was isolated from its community.

A scheme to promote community interest in the welfare of mentally handicapped people evolved, sited on unused Crown land adjacent to Turner Village.

This pioneering work was sponsored by the Colchester Evening Gazette and schools, colleges and individuals were invited to compete for monetary prizes in designing an educational area.

Many responded and a group of eighteen-year-old students on a building course at Ipswich Civic College were adjudged winners. As a direct consequence an exciting educational area was developed where mentally handicapped people could learn from sharing experiences with others more capable than themselves.

Such progress was possible only because Colchester people gave their wholehearted support. They not only contributed money, time and effort but also sustained the Charity's determination to provide mentally handicapped people with new skills to help them achieve a more rewarding life experience.

As Project Horizon became one of the best known local charities the needs of mentally handicapped people began to be recognised. The enthusiasm of the charity committee members who came from all walks of life hammered home the magnitude of the problem facing this deprived group.

Currently the situation is that in excess of £70,000, mostly collected by local people, has been invested in the site. However this is of secondary importance to the investment of volunteer time and effort which has, through shared work experience, helped many become more mature and better citizens.

The practical outcome has been the development of a site where many skills can be taught. Roads have been built to train users of electric wheelchairs. A lake has been engineered where geese and ducks nest and this provides considerable interest, especially when the goslings and ducklings take to the water. A

riding stable is being developed further to provide facilities for all physically handicapped people. A workshop has been constructed within which music, art and social therapies are practised.

In learning to care for animals mentally handicapped people become more emotionally mature and this has led in many instances to the achievement of better human relationships.

Arising directly from student involvement on the site strong links were forged with local schools, colleges and the University of Essex. One consequence was the residential conference at Essex University run jointly by the Charity with the University and the Royal College of Psychiatrists, the proceedings of which are contained in this publication. About two hundred people, parents and professionals, attended. A further conference is planned in two years' time.

Another link with the University is a research project designed to promote the use of microtechnology-aided teaching-systems to overcome communication problems facing the profoundly handicapped. This pioneering work is already yielding exciting results (see page 78ff).

We recognise with gratitude the interest shown by the District Health Authority in making resources available for this particular research.

We also thank the sponsors of the conference and the members of Project Horizon Specialist Committee, who put so much time into the organisation, and in particular Mrs Joan Ingle of Turner Village and Mrs Noreen Proudman of the University, who handled the correspondence. Our thanks are also due to Mr Bill Collins, the University photographer, who donated his time and expertise during the conference itself. We also wish to thank the following for their presence at the conference and for their interest in our activities: our Patron, Admiral Sir Andrew Lewis KCB JP (HM Lord Lieutenant of Essex); the Mayor and Mayoress of Colchester (Mr and Mrs Eric James); the Vice-Chancellor of the University of Essex and Mrs Sloman; Mr John Minter (Chairman of the NE Essex District Health Authority).

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COMMUNICATION PROBLEMS OF THE MENTALLY HANDICAPPED

PROGRAMME

Conference Chairman: Dr Robert McKibben
(Turner Village)

Friday 22 April

Chairman: Dr Joze Jancar
(Vice-President,
Royal College of Psychiatrists)

KEYNOTE SPEAKER

Professor Stanley Segal OBE JP
(Principal,
Ravenscroft Care Village)

Saturday 23 April

Chairman: Dr Joze Jancar
(Vice-President,
Royal College of Psychiatrists)

IMPROVING COMMUNICATION BETWEEN THE CARING PROFESSIONS

Mr Alan Davison
(District Administrator,
NE Essex Health Authority)

Dr Geoffrey Carroll
(District Medical Officer,
NE Essex Health Authority)

Mrs Dorothy Leighton
(Associate Director,
National Development Team for the
Mentally Handicapped)

USING NON-VERBAL SYSTEMS TO OVERCOME COMMUNICATION PROBLEMS

Mrs Margaret Walker
(Project Co-ordinator,
Makaton Vocabulary Development
Project)

Dr Chris Kiernan
(Thomas Coram Research Unit,
University of London)

COMMUNICATION DIFFICULTIES AND THE VISUALLY HANDICAPPED

Mr David Ellis
(Senior Clinical Psychologist,
Editor of Directory of Services for
Visually and Mentally Handicapped
People)

COMMUNICATION PROBLEMS AS A FACTOR IN BEHAVIOURAL DISTURBANCE

Mr Malcolm Jones
(Head of Beech Tree House,
Meldreth Manor School)

Options: Visit to Project Horizon
Makaton Vocabulary (Video)
or Free time

Demonstration
Microtechnology Systems for Handicapped People
Mr David Lyons
(Lecturer,
Department of Computer Science,
University of Essex)

Sunday 24 April

Chairman: Mr Peter Turner
(Headmaster, Whitefields School)

OVERCOMING PROBLEMS FACING PARENTS AND RELATIVES

Mr Tony Greaves
(Director of Nursing - Mental
Handicap,
NE Essex Health Authority)

Mr William Apps
(Parent, and Panel Member of the
National Development Team for the
Mentally Handicapped)

Mr Maurice Collins
(Parent)

Review of Conference

Mr William Apps
Mrs Barbara Dyer
Mrs Dorothy Leighton
Professor Stanley Segal

Farewell Mr John Roberts

KEYNOTE ADDRESS

PROFESSOR STANLEY SEGAL OBE JP MEd (Principal, Ravenswood Village for the Mentally Handicapped)

When I first saw the theme of this conference, a number of memories were stirred, and from these, by way of introduction, I propose to select two or three. First, I recalled the bold heading to an article in the Sunday Times a year or two ago on the first four Deaf-Blind Graduates at Moscow University. Deaf and blind. The article drew attention to the teachings of the late Dr Mescheriakov who had set the process in motion but did not live long enough to see this rich justification of his theory and practice. I was reminded that it had been a particular privilege of mine to have met Dr Mescheriakov almost twenty years ago, when I led a small British Council delegation to look at special provision in the USSR. And I can still recall the humanity, the momentarily revealed passion with which he recoiled against those in Russia as elsewhere who viewed deaf-blind children as vegetables; I can still feel the strength with which he protested that of course such children would be vegetables if they were merely left to vegetate. But if you held them physically; if you walked them; if you made them experience the range of normal pre-school experiences, from the use of the knife and fork to the use of trousers, you could then take them through a normal school curriculum albeit at a slower rate, provided the child was cognitively intact. And so a positive developmental, humane approach informed by scientific knowledge and backed by resources, transformed four presumed vegetables - about whom we would otherwise have known nothing - into four graduates, whose achievements had been communicated via at least one of the quality Sunday newspapers.

A second cameo was conjured out of Dr Pritchard's illuminating history of special education spanning the two hundred years from 1760 to 1960. It was at the beginning of that history - two hundred years before President Kennedy's imaginative, world-wide stimulus to interest in the mentally handicapped - that two schools for the education of children who were deaf emerged, one in France and one in Germany. The first was the creation of a compassionate and devoutly religious person who unlike earlier experimenters, was not selective about either his intake or their numbers. And although he started off by using the oral methods evolved by his predecessors, he found it easier, as the numbers grew, to turn to manual methods. By 1784 - in the book he published describing these methods - he was not merely convinced that speech was not necessary in the education of the deaf, but that it was not the best way of educating them.

With equal conviction however, an opposed view was pressed by the German teacher whose leading principle was that precision of thought was only possible where there was speech. He therefore openly discouraged a German student from studying in France, arguing that the teacher's approach there was harmful to education. The two teachers then engaged in a long correspondence - in Latin - during which each explained his own method, but apparently failed to read, to grasp or to answer the question or points raised by the other. It could be argued that the deafness of these two teachers to each other was a spiritual quarrel of a higher order than the one a century earlier, between two English teachers who each claimed to be the first to have described a successful method of teaching the deaf. Whatever other inferences such illustrations may lead us to, they offer at least this. They show that even though intelligent, articulate, literate members of the same profession may have difficulties in communicating, this does not automatically prevent them from helping children to communicate.

Now Dr Gordon Wells, the Director for the Study of Language and Communication at the University of Bristol, found it useful to think about communication as being based on a triangle; that of the sender, the receiver and whatever they are communicating about; or the speaker, the listener and the focus of their joint attention. It evolves from mother-child eye-contact being followed up by one or other looking at something else which is then brought into this interpersonal relationship, the adult usually following any show of interest on the part of the infant and saying something about it, and so on to the understanding of speech. Obviously such communication precedes speech as well as incorporates it. But we cannot escape the role of emotions, and some people might qualify the image of a triangle. They might point for example to the cries of infants which have become the subject of analysis by several of the professions which converge on the new-born babe. Such analysis is already being used as the basis for diagnostic instruments for use with both normal and abnormal infants. Further, in a book by that remarkable pioneer in the field of mental retardation, Dr Neil O'Connor, Language, Cognitive Defects and Retardation (1975 Butterworth), there is a particularly interesting contribution by Dr D M Ricks. He gathered together cries of hunger, frustration and so on from normal infants and young autistic children, and asked the mothers to identify their own children's cries, and the messages in the cries of the others'. Mothers of normal children could not easily identify their own child's cries but could identify the message in loud infant cries. Mothers of autistic children however, unerringly identified their own children and their messages, but could not identify the messages in the cries of the other autistic children. It is argued that such cries are not merely the precursors of language, but have a 'true language' function themselves. Auditory cues were sometimes less important than visual ones. W I Fraser and Dace Ozols asked nurses and mothers to explain, via a questionnaire, how they detected such conditions as earache, toothache, and so on, in profoundly handicapped children, and what action they took. Whilst all

agreed that cries, facial expression, aggression and so on played a role, mothers paid far more attention to facial expression than did nurses. The ability to judge or interpret - according to Fraser and Ozols - seemed to be dependent upon the level of experience with the individual child concerned, and was greatest in mothers. It was salutory to find that even the nurses in this experiment who were presumed to have had long experience with those specific children, proved no better at identifying emotions than did the untrained or inexperienced staff. This was held to be indicative of how little person-to-person communication there really was. We may even see here in embryo how easy it can become for a child to be viewed as a vegetable. Researchers were therefore not surprised to find that one special fear expressed by parents when their children were admitted to hospital was that nobody would know when their child was distressed. And one humane and useful inference was that the parents might be reassured if at the admission interview they were given precise requests for their knowledge of their children's pain and distress signals.

Communication in such cases involved interpretation on the part of the caregiver, the mother or other recipient of the emotional messages sent out in all directions by the distressed child. The caregivers, of course, also have emotions. Whilst I was preparing this paper, my wife drew my attention to a review by Patricia MacMillan (Nursing Times, 9-15 February 1983) of a book by Dr Kathleen Gow How Nurses' Emotions Affect Patient Care. The author - a lecturer in health studies - asked her students to write case-studies examining their emotional involvement with the patient, and assessing how far their reactions were helpful or otherwise in the outcome of total nursing care. Dr Gow started from an examination of the notion that nurses should not get 'emotionally involved' with their patients. We get nurses confessing to times when they could not cope, short-changed patients; left the patient in distress and even felt that the result of their actions was the death of the patients; but we also get case-studies where the nurse positively contributed to the growth and recovery of the patient 'not as an ego-message trip but simply because the nurse has sufficient insight to see how her, perhaps unorthodox, style of caring' made a dramatic difference to the well-being of the patient. The conclusion from over five hundred such case-studies was that there was a need for nurses to become emotionally involved, 'that affective neutrality simply does not contribute to good nursing care, and that nurses need to understand their reactions, to analyse their successes and learn from their failures'.

I have only touched upon this arresting review and have yet to read the book, but I do not believe that I have done either an injustice in presenting these comments. I suspect that I shall warmly agree with Patricia MacMillan's concluding remark that 'this is a superb book'.

Here were situations where both the patient and the caregiver could communicate with each other; other factors

entered the responses of the caregivers. And our communication triangle grows more complex. With echoes of Freud in mind we might also raise now the question of whom the speaker thinks she is addressing (as distinct from whom she is actually addressing) and what the speaker thinks she is saying as distinct from what she is actually saying. As far as infants were concerned, Fraser and Ozols viewed their distress signals as adaptive behaviour important to the child's survival and as part of what Dunn called a comforting system. We come to other issues when we consider the profoundly handicapped individuals described by them, who were no longer infants and who were held to be 'stultified in their adaptive potential by their own cognitive deficits and also by their experiences of idiosyncratic comforting at home and in hospitals' (Fraser, W I and Grieves, R (eds) Communicating with Normal and Retarded Children, John Wright and Co).

One further ingredient which I must isolate before they all act upon each other will no doubt bring to mind once again the philosopher who said, 'bring me your problems and I will complicate them'. For just as inability to speak is not the same as inability to communicate, so abililty to speak is not the same as ability to communicate. (Here I am not referring solely to the example of certain innocent birds whose ability to mimic speech has led to their deaths at the hands of infuriated listeners.) In addressing this multiprofessional gathering, I am not entirely reassured by my awareness that an inability to communicate despite speech is not confined to lecturers from any one profession. And I hasten to remind you that the title chosen for his pamphlet by the paediatrician Mervyn Fox, was drawn from a parent who said: 'They get this training but they don't know how you feel'. And professionals here who specialise in study of our inner lives, will already recognise that this paper cannot pay much attention to the dynamics or workings of our infra-structures, especially as far as communication with emotionally disturbed individuals is concerned. Fortunately, no-one here would assume that those who are cognitively intact - like the two teachers of the deaf referred to earlier - are automatically emotionally wholesome.

Similarly, we must not dismiss the possible input of sociologists, although they may be limited in their knowledge of special education. There may be such a concept as social wholesomeness. We each of us operate or function within a complex changing society, with which and within which we interact. And I think it may be helpful to repeat here a suggestion I made elsewhere, that as a framework to assist us in determining our position and charting goals, we might view ourselves as being influenced by three kinds of curricula; not just the school curriculum, which in turn incorporates what Jackson called 'the hidden curriculum' the ethos of the school. Preceding and incorporating this is what might be called the expanding family, neighbourhood and wider curriculum; that is, the kind of curriculum which existed before any state school system was invented and which over the years has driven people who originated from the same stock in this country, to

differentiate into separate nations, or has welded people who originate from different parts of the world into one nation; enables a child from south of the border to be distinguishable from one north of the border, whilst enabling both to be recognised as British. Differences of such a kind might be viewed as the end-result of vast, unsystematic behaviour modification processes, inconceivable without communcation. Finally there is the chance curriculum, the one specific to the individual. Within this changing context we see immediately that those who conceived and planned this multidisciplinary excursion, are light-years ahead of the teachers of the 1780s, and of the social and technological bases of that period.

These proceedings are focussed upon individuals who are mentally handicapped and not upon those whom Meschériakov described as cognitively intact. And because so little is known about the workings of the damaged brain; because individuals with only slight damage may lack speech whereas some very severely handicapped individuals can speak; we would want to congratulate Dr McKibben and his specialist committee all the more for bringing together here distinguished and compassionate scholars and practitioners, who can help us classify and penetrate further into certain grey matter, so that we might emerge with a better understanding of the nature and role of non-verbal systems of communication; so that we can reflect more - in context - upon parent-professional understanding and partnership; so that communciation within and between professions might be assisted; and so that we can know more - also in context - about the emerging microtechnology systems whose promise is currently arousing a great deal of excitement.

You may be interested to know that earlier this very week, the south-west region of MENCAP held its 16th Congress on the themes, 'Emotional Responses of Mentally Handicapped People', during which they held symposia on transitions, bereavement and on expression. (MENCAP, 17 High St, Taunton, Somerset TA1 3PJ)

* * *

Technology has played a considerable part in enlarging the mobility and freedom of physically handicapped individuals. When the Special Education Bill was being examined by the All-Party Committee at the House of Commons, with a view to improving the impending 1981 Education Act, one MP closely connected with POSSUM claimed with justifiable pride that he could bring into a prepared room a handicapped individual who was barely able to move a muscle, yet by means of two small such movements, or even the ability to puff and blow, would be able to open doors, draw blinds, make his needs known, and so on. In the school for the physically handicapped of which I was once head, children could be launched into communication by means of Possum equipment, and a colleague recently wrote that the Possum basic skills machine is particularly useful to his school, because of its size, light stimulus, and immediate reinforcement through extra programmes.

Using this machine he said a pupil was able to do the same work as the rest of his class. Microtechnology however, has now outstripped many of the uses to which Possum had formerly provided the only aide, and he adds: 'We have a few children who have never been able to use Possum but who are now succeeding with a computer. . . '

You may have seen that remarkable, inspirational programme, Finding a Voice, produced on television by Dick Boydell. In it, assisted by the new technology, we saw two intelligent people so afflicted by cerebral palsy that it was a laborious exercise for them to say even the simplest of things, yet enabled by means of a micro-processor attached to their wheelchairs, to select phrases and words which the machine produced for them and which enabled communication to take place at a normal conversation pace. The potential was breathtaking in more senses than one. Like Mescheriakov's students, however, these handicapped adults were cognitively intact in so far as their ability to develop meaningful language was concerned. Their major need was for an alternative to their own, damaged speech production mechanism. We face a more comple challenge. Our concern is not those whose peripheral mechanism of speech is handicapped, but with those who suffer from more central destruction to their output. We do not even know if their language develops in the same way as with the rest of us. We must begin somewhere however.

The obvious approach to developing communication in handicapped individuals is to be guided by our model of normal language. And during the 1960s, when Chomsky's views held sway, it was accepted that syntax was the key to language, and that normal children probably had an innate disposition towards acquiring syntax. From this it was inferred that handicapped children required a structured programme which would help them to develop whatever inborn language structure they might possess. Fortunately this interpretation of normal child development was seriously questioned in 1970 by Bloom, who stressed the importance of meaning instead of structure. Utterances like 'mummy shoe' for example, could have different meanings in different contexts. Piaget-based studies fitted in with this line of approach, showing the correspondence between language-development and the cognitive-development of the child as the child gradually discovered for example the permanence of objects outside him. Ivan Leudar has sketched the evidence which underlines the shift in approach from the focus on syntax; linguistic competence; to a study of the way we use language, including current interest in the preverbal communication of children, non-verbal communication in adults and finally, to the organisation of communication. In drawing attention to the revolution in the methods of teaching children with severe communication problems which occurred during the 1970s, he notes too, that whilst this shift is marked in the studies of the communication af average subjects, with some exceptions a parallel shift is long overdue in the field of mental retardation. Because there was so little relevant research in this field Leudar, instead of summarising it, provided instead a

framework for the study of communication. And he suggests that the communicative environment of the mentally retarded is systematically distorted; it does not allow them to engage in certain overt speech acts, and forces them to communicate covertly. Many of us will know of mentally handicapped individuals who appear to communicate with each other although we cannot interpret their interplay. There is a huge area for experiment here. I notice that Asher Cashdan, Director of the School of Communication at Sheffield City Polytechnic, divided his paper last year on Language and the Child with Special Educational Needs, into five areas which began with one headed, against language development. Working with normal three and four year olds in nursery groups he explained why he thought that language development was a bad thing. 'The first group of reasons is to do with means and ends. I don't want my language to be better so that I shall have better language. I want to be effective when I've got something I actually want to talk about'. Language had no value in itself, it was a tool for a task.

You will not expect me to say much here about areas on which other speakers with greater experience and recognised authority, will be addressing you. I do however, want to touch upon a few issues which occurred to me as I prepared this paper. Professionals who have worked in the field of the deaf, have created a number of non-vocal systems, and we owe a great deal to such pioneers. It is instructive to find that the British Sign Language for example, is an actual language in its own right; a foreign language which must be taught and learnt. Fascinating as this fact is, the BSL as such cannot be central to our purposes. It is not like an esperanto for the deaf. There are some signs used, identical to those in the American Sign Language, but which mean very different things. Its grammar does not mirror spoken English and its signs do not translate directly into English words. Several variants of BSL have been designed which use the order of spoken English. Signed English, the Piaget-Gormon Sign System and Makaton are all variants which aim to use the order of spoken English. However, unlike teachers of the deaf, we have two major groups of problems which make our task more difficult than is theirs; firstly we are more or less compelled, like mothers of infants, to follow any interest of the much older mentally handicapped pupil and to seek to draw what his attention fastens onto into our interpersonal experience; secondly because our pupils appear to learn little spontaneously, we may find it essential somehow to structure our teaching. Dr Kiernan has already observed somewhere that the development of communication in mentally handicapped individuals may not be delayed, but different from that of the normal child in several important ways.

Whilst it seems that we must experiment with approaches which move from the sounds, gestures, pictures and so on to more complex language functions, I have also been haunted by the obvious fact that even intelligent people, within the same country, using identical terms, can signal very different images to each other. This is not communication. Warnock for example

found it necessary to define three kinds of 'integration', locational, social and functional. One can certainly sympathise with Charles Bliss who was born in pre-war Austria where some twenty languages were spoken and who - in his efforts to teach the deaf - was prompted to create what he called a logical system for an illogical world. Even at concrete levels of communication the challenges are considerable. And if you wish to know more about Signs Symbols and Schools, a most valuable little publication with that title has been published by the National Council for Special Education and includes lucid articles by Dr Kiernan, Margaret Walker and other researchers and practitioners, and has helped to caution me against the incorrect use for example of the word 'rebus' which I had assumed to extend to actions, relational concepts and other semantic elements.

I have already made references at one extreme to the use of micro-electronics - and at the other to the questions of emotions, attitudes, and so on, (dimensions of our own makeup which we do not automatically consider when it comes to communication with pupils). When I first heard of micro-computers being used in schools I must confess that my first response probably belonged to the same stable as did that of our Victorian grandmothers who refused to board the Iron Horse. There seemed good reason to desregard this new means of educational transport. It was still at the experimental stage with pupils of normal intelligence. What relevance could it have to pupils who were so handicapped that they were confined to beds or wheelchairs, indicating little response to their surroundings? And how to use such complex machines with hyperactive pupils or those who exhibit bizarre behaviour problems? Warnock was appointed ten years ago - in November 1973 - to head a Committee which reported in 1978, and its committee could not have been expected to foresee the rapid development of microchip technology during the subsequent five years. I now believe that had the Warnock Committee been able to foresee this development they would almost certainly have included a recommendation for their multidisciplinary team approach to include technical experts with knowledge of electronics, computer hardware and software, and associated fields. We already know of scattered efforts by teachers to improve the motor control of their pupils, to reduce behavioural problems, and to provide a more positive approach to the education of their pupils consequent upon the use of the new technology, notably in the area of communications. (I recently wrote to the small number of special schools for the physically handicapped, where I had learned that these had had experience of both the use of Possum equipment and of micro-computers, and there were enthusiastic responses about ways in which the micro-computers had overtaken and left behind functions which until then had been provided by far more costly as well as less efficient equipment - at least for the specific needs those schools were seeking to meet).

It was only in March 1980 that the Minister of State at the DES announced the Micro-electronics Education Programme, a four-year operation funded to the extent of nine million pounds. The

aim of the programme is to help schools to prepare children for life in a society in which devices and systems based on micro-electronics are commonplace and pervasive. Also the technology was to be used by teachers to encourage learning. These MEP activities are one third national and two thirds regional; the latter activities being divided into Information, Inservice Teacher Training and Curriculum Development.

A special education committee was set up as part of this programme. At first it was hoped that this committee would be able to set up resource centres for at least each region but the financial constraints had their effect and so far only four centres are operating, called SEMERCS, special education micro-electron resource centes, which aim to take relevant materials to schools as requested. The work is still in its infancy of course, but very relevant to our theme. It is hoped that each SEMERC will include a specific, in addition to a general expertise, eg, with the visually handicapped. With regards to mentally handicapped children some scattered work is already taking place. Independently Ravenswood has held two think-tanks; firstly to discuss whether micro-electronics had anything to offer any of the mentally handicapped residents at Ravenswood; and the unanimous view of the experts assembled was that almost the entire population of children, adults and staff could benefit. The second think-tank got down to the problem of what to do at Ravenswood, and from this an investigative study followed. Two things are currently happening. Firstly a research programme is being designed and if funded will lead to a three-year project. I shall add to this comment shortly. Secondly, as part of Ravenswood Week in the coming June, I am arranging a workshop at which everyone we discover to be doing relevant work with mentally handicapped children and micro-computers can be brought together.

The coherence of the curriculum for each individual pupil provides a complex cluster of problems to be faced. It seems - to our team - that we might utilise the new technology in two main directions. Firstly, the more detailed collection and analysis of each pupil's responses in order to determine future activities (such data collection could include visual and auditory information as well as what is accessible via the micro-computer); secondly we could harness the speed and power of micro-processing to allow much faster and more varied adaptations of situations in response to the analysis from the previous central tenet.

In this way we believe it will be possible to move from what is today too often a predominantly behaviour-based approach towards a more problem-solving, child-centred philosophy underlying the curriculum for each individual. Because the basic applicability of the technology had to be demonstrated, and because our proposals present many more and more difficult technical problems to solve, it cannot be surprising that our field is only just at the beginning of raising such questions. However, amongst the aims my colleagues are now seeking to set

themselves are to find ways, by means of a facilitating environment, to reduce the effects of what one researcher has called 'learned helplessness' and/or non-adaptive behaviour in those with severe physical and mental handicap.

An example of specific case studies proposed from each of the three main subdivisions into which we have divided the residents at Ravenswood may help. In the case of one schoolchild, for example, who appears to have some comprehension of language but appears unlikely to learn to speak, the ability to lift an arm and point provides a base for action. It is hoped that with appropriate stimuli this girl's motivation will be increased to enable her to use arm movements which at the moment show weak directional control, for the purposes of communication. With our more severely handicapped adults, the scope for one-to-one attention is obviously limited. It is also very difficult to create stimuli and situations which are powerful enough to hold the attention of some very disturbed and very handicapped individuals. Whilst individual attention cannot be replace by contact with machines, one aim is to see how modern technology might help further stimulate and enrich the lives of such residents. Thirdly, for adults who could use a standard keyboard (or one modified to meet their needs) existing software, and notably such software suitably modified, offers scope.

I think it is generally accepted that multiprofessional efforts to educate individuals whose cognitive processes are distorted or severely restricted, are comparatively a recent phenomenon. To fasten on a date, I would cite the year 1960 - the very year in which Dr Pritchard's history of the handicapped came to a close - as the very year in which the first social rockets with space-age potential, were launched. I even suspect that Dr Pritchard, in a new edition, might wish to add to the statement which appears on the first page of his book. When observing that schools for the handicapped did not begin to appear until the second half of the eighteenth century he went on to write: 'that they should lag behind was understandable, for educational social trends are followed, not created, by provision for the handicapped'. Many of us would not, in other circumstances, question the inference. We might even infer that it was logical for provision for the mildly handicapped to precede provision for the severely handicapped; or for the provision for those with minor learning difficulties to precede that for those with more pronounced learning difficulties. But the process is not nearly as neat or as logical as this, and I suggest that the 1960s not only marks off for us an important, qualitative change in the UK educational approach to children who were then still being excluded from the education system - the children with IQs not exceeding fifty - but that with the new approach, even as Dr Pritchard was making his broadly acceptable generalisation about provision for the handicapped following and not preceding educational and social trends, a new educational phenomenon was making its appearance outside the state education system, which was to have far-reaching repercussions within it. In 1960 - World Mental Health Year as it was named, and may yet

justify - two different multiprofessional launching grounds with fuel drawn in part at least from the expanding parent movements, launched two different but overlapping international conferences, each of which was designed in ignorance of the other. The first was labelled the London Conference on the Scientific Study of Mental Deficiency (today the International Association for the Scientific Study of Mental Deficiency) in which clinicians of various kinds provided the main thrust; the second, in which teachers provided the main thrust was the first International Conference on the Education of the Backward Child. Both conferences were rich in multiprofessional input, and those who planned and launched these developments coalesced with yet other forward-moving, small but growing organisations in the sparkling 1960s, and together these so informed the thoughts and feelings of a sufficient body of decision-makers in this country, that by 1970 there was a virtual consensus in the House. For the first time we had an Education Act which brought every child of school age in this country - however severely handicapped - under the educational umbrella. And that development in turn was the stimulus, the major teaching aid which led to at least two further developments of major importance. Firstly, the campaign for a public inquiry into the entire area of special educational needs; a campaign which had begun in 1966 (which had won over the opposition in 1967, but which was nevertheless still resisted in 1970 by the then Secretary of State for Education and Science). That 1970 Act, the admission into the education system of children with severe learning difficulties, was the additional factor which helped more politicians, professionals and members of the public to cry out for, as well as to grasp the need for an inquiry which was not to limit itself to the two percent of children who were ascertained as in need of special-school type education, but the twenty per cent of whom the vast majority were being overlooked in ordinary schools. Concern for the needs of the most severely handicapped child was helping to reverse history, was leading the way to improvements in the education of more able children.

The fuller significance of the 1979 Act can now be detected. Until 1970 it was still possible for compassionate people to be bewildered as to what to do, whilst the wilfully deaf skated as always over the gross inequality in our educational provision. Pressure groups with differing competences in communicating with decision-makers, competed, leaving some areas unrepresented or under-represented; and the 1944 consensus dream of selection of each child for an appropriate education according to age, aptitude and ability was steadily distorted into a process of selection of some. Economic constraints assisted the tilt from 1944, even though the base level was rising. The rewards for teachers, pupils and parents were plainly seen to be in the A stream towards which certain groups pushed increasingly. And from the succession of investigations which were to take place into hospitals for the mentally handicapped, it was to come as a shock to many that the 'end of the road' was not their selection for specialist treatment, but situations which were intolerable in a civilised society. Whilst I was preparing this paper,

another report described a high-risk situation due 'to the vicious circle of underfunding, understaffing, overcrowding and poor environment'.

Within the school system it was still possible right up until 1970 for the compassionate to reassure themselves by reference to so-called 'removes' within ordinary schools for small groups of 'problem' children; or by insisting that classes in the lowest stream should not be as large as the rest - even if the teachers were not appropriately trained for such pupils (and even if, at times, the teachers were themselves not thought to be that competent with normal children). They could point to a growing number of special schools and the special training of teachers for the tiny fraction of the population who could not cope within the ordinary school, even if there was a skew towards those with whom the ordinary school could not or would not cope; those who did not fit in with schools which measured achievement by reference to their A stream successes in the main. And considerate teachers in the 1960s could assume that those debarred from, or spilled out of the special schools, were at least in the hands of highly skilled medical personnel - not thrust back into tormented families, handed over to inappropriately trained, if dedicated staff, and crowded into one of those wards which the late Professor Jack Tizard and others began to diagnose in the 1950s. But with the 1970 Act; with the 1971 White Paper on Better Services for the Mentally Handicapped; the rejection-syndrome which had been evolving within our society to its detriment, was laid bare.

Protests by involved teachers in particular grew louder (and had parallel within the health system) that the system of creaming and streaming had been gathering a tide of rejection, which carried with it unhealthy emotional over and undertones. And if that tide carried a great deal of froth, along with the flavour and values of single-minded individuals preoccupied with the cognitive skills of the able, a check was inevitable. And we must now view the tide towards integration, mainstreaming, normalisation and community, nothwithstanding its froth too, as the healthy counter trend, assisting our society towards balance and bringing with it warmer emotions related to fellowship, compassion, and the various dimensions which distinguish human beings from animals.

To conclude: Communication involves attitudes, emotions, a wish to interpret - whether it concerns professionals or their handicapped clients. We have simultaneously to improve our expertise and our ability to communicate our findings. We seek to do so conscious that our central focus is upon how to improve the quality of life for those individuals whom - despite the nation's impressive achievements - it could not save from handicap.

COMMUNICATION BETWEEN AGENCIES

DOROTHY LEIGHTON (Associate Director, Development Team for the Mentally Handicapped)

The services required by the mentally handicapped and their families are currently provided by five statutory agencies including three central government departments and a variety of voluntary and private establishments. For this client group, more than for any other, it is essential that these agencies work closely together. To dovetail their services, as they are used by the clients both together and in sequence. At any one time the mentally handicapped child or adult may be both a school pupil, a health service patient, a social services client, a social security beneficiary, a trainee, a housing tenant and a user of voluntary provision. If the services are not integrated then gaps or duplications may occur which result in the handicapped person being deprived of the help needed or having to seek that help a long way away from his home. For the families seeking satisfaction of their needs the impression is of being alone in a jungle without maps. This jungle is man-made and it is worth spending a little time to consider how it has come about.

In the nineteenth century the mentally handicapped formed part of the group of society's rejects dealt with by the Poor Law, so that they could end up in the Poor Law Institution along with the aged, the sick, the mentally ill, the indigent and the immoral. The Victorian philanthropists at the end of the century campaigned for a separate service for the mentally handicapped, and the campaign culminated in the Mental Deficiency Act of 1913. This Act placed responsibility on the local authorities to provide for all mental defectives classified as idiot, imbecile, feeble minded and moral defectives, by certifying them and providing institutional care. As there existed a fear of the virility and intelligence of the race being threatened by the excessive breeding of the feeble minded, these institutions were well removed from society, often strictly segregated and probably for life. Some community care was available but under licence or guardianship so that the person could still be strictly controlled in their behaviour and returned to the institution if lapses occurred. However misguided we consider it to be in the light of current thinking it was a complete unified service.

The first change occurred in 1948 when the institutions were handed over to the new National Health Service, and they continued to provide the bulk of residential care, together with some voluntary and private homes.

The next significant step was the passing of the Mental Health Act of 1959 which introduced the concept of community care, established the Mental Welfare Officer within the local health authority and incidentally linked the mentally handicapped with the mentally ill in both legislation and in the public mind. The responsibility for community care was placed on the local authorities, but as they had handed over their institutional provision only eleven years before, there was very little enthusiasm generated for setting up new forms of residential hostels. There were, of course, some exceptions, notably Lancashire where a research project was mounted to explore the advantages of moving mentally handicapped people into smaller units in the community. However the community did not appear to be ready to welcome the move and the hospitals were still seen as being the major providers of residential care. The presence of the Mental Welfare Officer did offer a focal point for families and his disappearance is now much regretted by many parents who saw him as someone known to be identified with the mentally handicapped, and to whom they could turn in times of stress.

At the end of the 1960s the overcrowding and understaffing of the mental handicap hospitals led to scandals which awakened public concern. Mental handicap had become a low priority in the NHS concerned with developments in other parts of the service. Clearly a government initiative was needed and a new policy document emerged under the title of "Better Services for the Mentally Handicapped" in 1971.

"Better Services" attempted to encourage community care by identifying the task of the two major agencies of health service and local authority by dividing care into medical nursing needs and social needs. The local authority was expected to provide for those people who needed residential places for social reasons and to provide sufficient day care for the vast numbers of mentally handicapped people who continued to live with their families. It is perhaps often forgotten that even in 1971 eighty per cent of mentally handicapped people were cared for in their own homes.

The local authority now being exhorted to build up community care was not the previous local health authority, but the new "Seebohm" department of social services, generic in its concept and without identified Mental Welfare Officers. The target figures provided by the new Command Paper was regarded as helpful and most authorities set up plans for increasing both hostels and adult training centres, until the problems of economic constraints put a damper on both captial and revenue developments.

Also in 1971 a further, far-reaching change was initiated. Education of mentally handicapped children became the responsibility of the Education departments and the much resented exclusion was swept away. The junior training centres previously run by local health authorities and the hospital schools became the basis of a special education service entitling all children

to a place in a school suited to their needs.

Cash and welfare had been separated under the welfare state and benefits and allowances to the mentally handicapped are now part of the social security system. This has introduced many problems in reconciling different philosophies and understanding of needs, and indeed has produced conflicts, now fortunately being eradicated, in short term care available in health service accommodation and local authority hostels.

One further agency now increasingly important for the mentally handicapped is the housing authority. Growing use of group home tenancies and sheltered housing has brought problems in the availability of the public sector to people hitherto resident in hospitals who may have come from other counties and whose years in hospital have not produced a residential qualification.

The voluntary and private sector which might have been thought to be superfluous in a comprehensive welfare state has in fact continued to expand as gaps emerge, particularly in the care of the multiply handicapped and the disturbed mentally handicapped for whom the two major agencies have insufficient provision. We have, up to now, been unable to cope with the problem of moving the large number of people still in hospital who should properly be living in more independent facilities, and hospitals have not fully appreciated the need for the provision of specialised care for the most difficult groups. Both agencies are therefore forced to seek this service in the voluntary and private field.

The fragmentation of services has resulted in a need to provide for some form of joint planning if there is to be any sensible continuum of care. To this end Joint Consultative Committees, Joint Care Planning Teams and working groups have been established. The co-operative spirit has been enhanced by joint financing to encourage the major agencies to identify needs and gaps and plan together. The new care in the Community circular has instanced ways in which money can be transferred from health to local authorities as the people from hospital move out. However the big obstacles to joint planning still remain and have been intensified by the most recent health service restructuring. The greatest problem is one of boundaries. Very few coterminous health and local authorities exist. Counties may be negotiating with four or more District Health Authorities. These DHAs may not correspond with local authority districts, nor with social service and education divisions or areas. Different planning procedures and financial sources make for lack of mutual understanding and the effect of political bias in local goverment is not always fully appreciated. Finally priorities are very different as local authority social service departments put most emphasis on statutory duties and child care, while many health authorities now place mental handicap high on their priority list.

To illustrate how services for the mentally handicapped may be affected by this complicated organisational pattern it is worth examining the provision of special day care for the profoundly, multiply handicapped and disturbed mentally handicapped. "Better Services" assumed that this might be provided in day hospitals. This was not acceptable to many parents who, while willing to continue care at home wanted day care available near their home and not in a remote hospital. Many local authorities responded to the parents' wishes and set up special care facilities within their Adult Training Centres and eventually DHSS policy modified to accept this as the proper location for this special care. Education authorities had already introduced special care for this group in most of their ESN(S) schools. The skilled professionals needed to help with this group are mostly employed by the health service. They include psychiatrists, clinical psychologists, nurses, physiotherapists, occupational therapists and speech therapists. The old school health service appears to have survived the 1974 re-organisation of the health service and together with educational psychologists give support in the ESN(S) schools. The service to adults unfortunately in many places seems to have remained locked up in the hospitals. Without this professional support special care is difficult to supply and even if provided may become merely a static holding operation rather than providing active programmes designed to minimise the disabilities of the people attending. This is discouraging enough for those trying to care for the physically and sensorily handicapped but renders the active treatment of the disturbed, hyperactive person well nigh impossible. Further problems arise in providing short term relief care to this group, many of whose parents are reluctant to accept a hospital they have been trying to avoid by their continuing care of their child in their own home.

There are still examples of neither of the two main agencies being able to agree on the provision of fully supported special day care, and this being left to the voluntary field. Success varies and some voluntary special care units provide a model of good practice. Others are desperately trying to involve the statutory agencies as they measure the magnitude of the task. It is a major criticism of joint planning if the care of the most difficult has to be left to the voluntary and private field.

What needs to be achieved for the mentally handicapped and their families is a situation where any door they approach will lead to the service they require. Moving from one service to another, for example from school to adult day care should be anticipated, planned and without pain. The most needed should be near at hand, freely available and approachable. Skills available in one agency should be shared with others in order to enhance the service given. No one discipline should consider that it has the complete answer to the needs of the mentally handicapped nor the right to direct the skills of other professionals. The approach should be multi-disciplinary with a key worker co-ordinating the service to the family. Progress is being made in this direction by the community mental handicap

teams at grass roots level. This needs to be matched by convincing joint planning directed towards establishing a comprehensive local service, backed up by specialist services available in times of crisis. The aim should be to minimise the disabilities of the mentally handicapped to enable them to live as independently and normally as they can. Risks must be shared also, as allowing more independence will always entail taking chances but the mentally handicapped cannot exist in cotton wool cocoons. If they are to enjoy life to the full they must also be allowed to risk a little - they are after all citizens of this risky world.

IMPROVING COMMUNICATION BETWEEN THE CARING PROFESSIONS

GEOFFREY CARROLL (District Medical Officer, NE Essex Health Authority)

To develop a comprehensive community mental handicap service in a cold economic climate requires leadership, creative management and collaboration between professional groups both in the Health and Social Services.

National Development Team reports provide incentive to change and Regional Health Authority guidelines the directives. District policy is expressed in Operational Plans as capital programmes and investment in manpower and skills. The closure of a large mental handicap hospital in this District is the opportunity to seek allies in Social Services for Joint Care management by the innovative use of funds released by the sale of the estate.

Kenneth Clarke, Minister for Health on 14 March 1983 announced new initiatives to help get people out of long stay hospitals and into the community. The most important change is that for the first time ever health authorities will be able to offer to local authorities and voluntary organisations continuing payments for as long as necessary to provide for people moving out of hospitals into community care. It will be possible to move resources with the patient for however long it proves necessary to provide him with better care at or near his own home. This goes much further than the so-called joint finance arrangements which provide support finance only for a period.

By reaching agreement with Social Services on appropriate placement and staffing in community units we can make real progress.

The management of change requires adaptation of the medical/nursing model to the new philosophy of the site and nature of services required.

Three assumptions underlie changes in policy related to care in the community of the mentally retarded in the last decade.[1,2] First, that large institutions have failed to increase the competence of their residents. Such environments may, in fact, have been detrimental to the development of motor skills, communication skills, learning skills and competence in general.[3,4] Second, that an environment proving 'normal social contact' and the potential for 'normal social interaction' has a positive 'normalising' effect on the mentally retarded.[5,6]

Third, that community-based residential facilities provide this relatively 'normal' environment. By definition [5-7] they are houses or flats indistinguishable from the rest of the neighbourhood. They are family-like with smaller numbers of residents than are found in institution wards or sub-units. They may have a higher staff-resident ratio than institutions - implying more individual care for the residents. Therefore these facilities are expected to have a 'normalising' effect, ie an increase in competence ensues.[8,9]

It is argued that where people live, in particular, should form the basis of any service delivery system.[10] During the 1960's Denmark[11] and Sweden[8] re-evaluated their residential models and consequently began to place the handicapped near population centres to provide the programmes with a full complement of back-up services. Existing institutions were remodelled and small community-based hostels were established. At the same time, medical, educational and vocational services were expanded and a national three-year training programme for staff members was established.

The principle of normalisation underlay these changes and was first proposed by Nirje and Bank-Mikkelson and later expanded by Wolfensberger. It means 'making available' to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of mainstream society. The awareness that mostly only relative independence and integration can be attained is implied and stressed by the words 'as close as possible'.

Key questions are:

> How do we ensure that the right mix of skills are available to organise and to deliver care in the community?
>
> How do we evaluate the quality of care provided?

Let us consider briefly the relationships, actual achievements, potential developments in the provision of a service by several professions viewed alone and from the viewpoint of collaboration with administration, medicine and nursing.

The role and objectives of occupational therapy must be re-expressed and defined in a multidisciplinary context to provide a service in four main areas: assessment, treatment, rehabilitation and maintenance. The strength of occupational therapy lies in the identification of areas where therapy can help in further treatment, by defining intermediate goals, and pacing individual programmes to patients' abilities. Occupational therapists have a knowledge and perspective which enables them to discover and train patients' potential abilities, helping them develop the required skills to function at a higher level and to enjoy a better quality of life. The department

itself is also a treatment tool, offering a controlled area where behaviour can be directed in specified channels (with co-operation of the ward staff in habit training and a psychologist in behaviour modification). Occupational therapy reports are translated into programmes for action by constant communication between nursing staff and occupational therapists.

Dramatic changes have taken place in the care of the most physically handicapped residents over the last fifteen years. With co-operation between physiotherapy and nursing staff substantial improvements in the daily lives of the residents have been achieved. Many residents who were immobile are now able to walk a little with aids, and can stand with aid, which helps nursing procedures, dressing and toileting. The collaboration with rehabilitation nursing staff who were trained by physiotherapists in hydrotherapy techniques has opened up an area of enormous potential especially in the treatment of handicapped children.

The development of communication systems is not just the province of speech therapists but the responsibility for all who are associated with mental handicap. However, it is essential for speech therapists to assess and advise on systems suitable for individuals. Evaluation of recent initiatives shows that the general management of patients becomes more effective with the involvement of speech therapists in multi-disciplinary projects. Examples include the pre-school assessment necessary at Lexden Springs School; workshops for parents of mentally handicapped children; Makaton courses for nurses, parents and other professions; and a home teaching scheme initially with a Down's Syndrome child extended to other mentally handicapped children with outstanding communication problems.

The policy of integrating mentally handicapped patients into the community will offer a challenge to Health Education staff to work in collaboration with nursing and medical staff to improve not only the attitude and acceptance of local communities to the mentally handicapped but also to improve the health knowledge of patients and their ability to make basic decisions concerning self care.

I believe alteration in the traditional roles of the care-givers will take place supported by flexibility in budgets with substitution of care staff for nursing staff, of nurse behaviour therapists for psychologists, of physiotherapists for nurses and of occupational therapists and psychologists for some of those involved in the development of assessment and training programmes.

A new generation of methods to measure and evaluate quality of care in community units is required.

To illustrate the form and content of the evaluation I will draw on studies[12] which I completed on community based residential units for the adult mentally handicapped in Ireland.

Seventeen units identified as (a) community based and (b) alternatives to institutional care, controlled by eight organisations, were included in the study.

Five dimensions of care-taking practices were measured using scales: the extent to which management practices were resident-oriented; the quality of the physical environment; the responsibility of residents for household tasks; their independence in self-management; the extent of contact with the community. Organisation staff: medical directors and administrators and care staff in the units were interviewed to (a) examine the goals of the organisations from the perspective of staff at different levels and (b) to describe aspects of the organisational structure and process of delivery of care.

The extent of consultation between care staff and organisers and care staff's participation in decision-making was measured using a further index.

Information on the hundred and sixty residents in the seventeen units (Figure 1) (demographic, aetiology and level of retardation, physical disabilities, behaviour characteristics, source of admission and vocational placement) was recorded by questionnaire.

Following discussions with staff in Ireland and at the London School of Hygiene and Institute of Psychiatry, it was decided to explore five dimensions of care, using scales, each measuring discreet dimensions of care-taking practices. Three had already been used in previous studies of care[13,14,15,16,17,18,19] and shown to have a construct validity which makes them suitable for this study.

The Revised Resident Management Practices Scale (RRMP) was developed by Raynes et al[15] (Figure 2) This measures the extent to which the management of daily and other recurrent social situations is organisation or resident-oriented. Items of the RRMP were selected to represent issues identified by Erving Goffman[20] as determinants of the quality of care. Care staff are interviewed to examine the degree of flexibility of routine, whether the residents are dealt with as a group (herded) rather than as individuals, the opportunities for personal possessions or privacy in the residents' environment and the degree of social distance maintained between staff and residents. (Twenty eight items are scored on a three-point rating scale and summed to give an overall score.) The lower the score on this measure the more resident centred the care practices. The possible range of scores on this measure is 0-56. The reliability (inter-rater) is reported[19] on this measure at 0.96.

The second measure developed by Raynes et al[15,19] is called the Index of the Physical Environment. This is a measure of the facilities available to the residents. Twenty two items relating to physical amenities were scored on a five-point rating scale. The items in the scale relate to three of the living areas in the

FIGURE ONE

Scores on Index of Participation in Decision-Making by Care Unit

(Lower scores indicate greater participation by care staff),

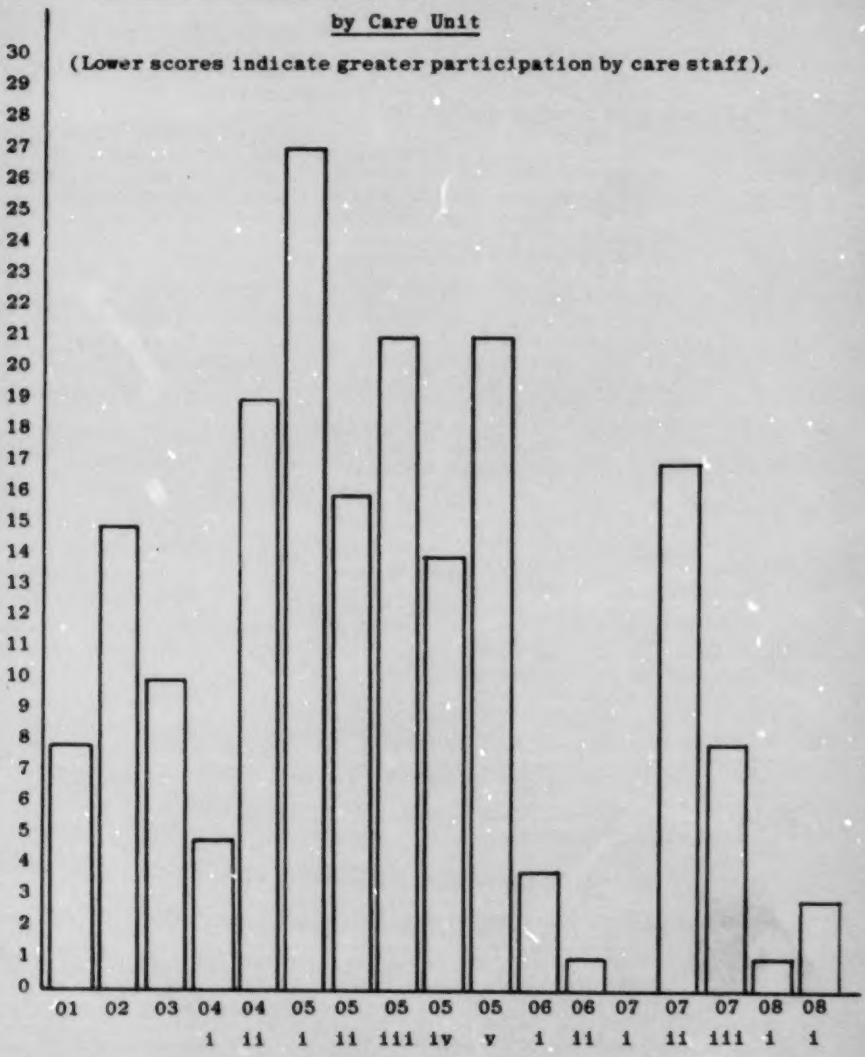
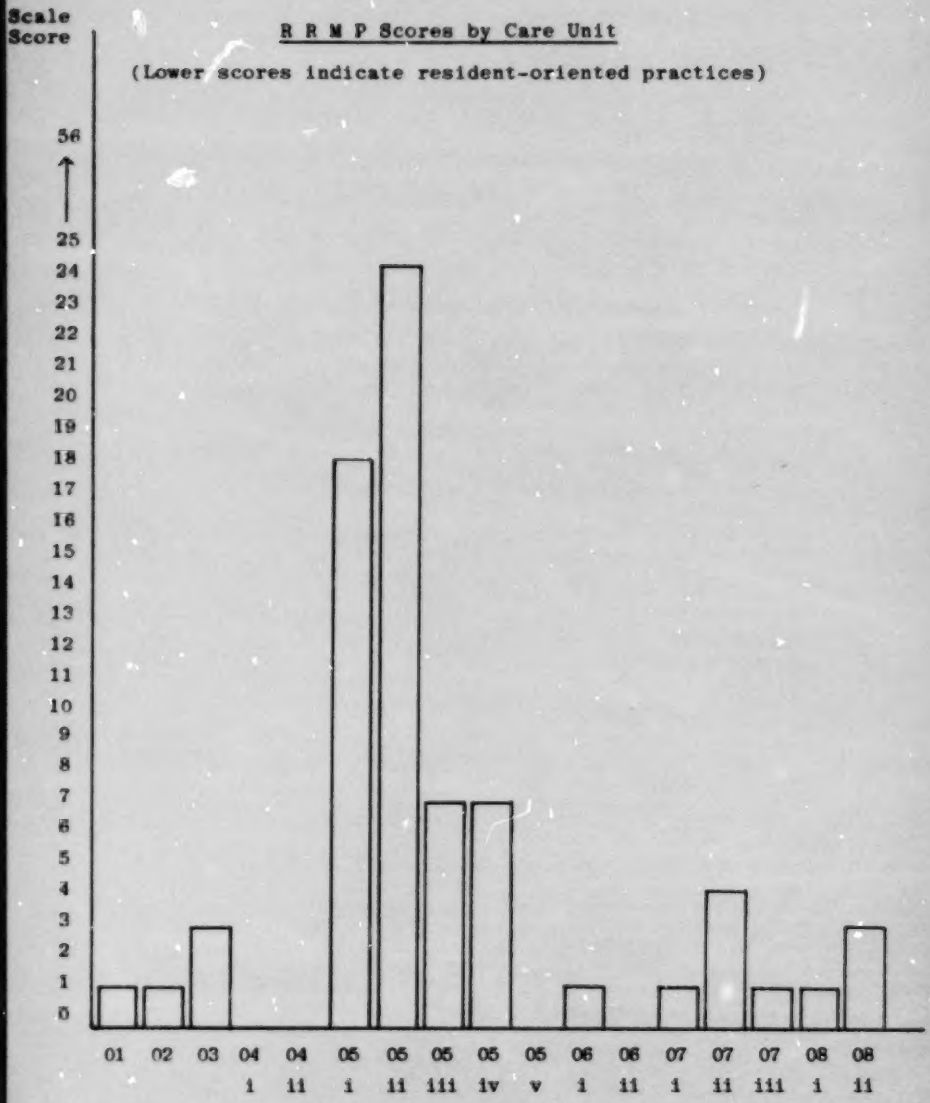


FIGURE TWO


Scale Score
R R M P Scores by Care Unit
(Lower scores indicate resident-oriented practices)
56
25
24
23
22
21
20
19
18
17
16
15
14
13
12
11
10
9
8
7
6
5
4
3
2
1
0
01 02 03 04 i 04 ii 05 i 05 ii 05 iii 05 iv 05 v 06 i 06 ii 07 i 07 ii 07 iii 08 i 08 ii
Organisations (01 to 08)
and units within (i to v)

community-based houses or homes - dayrooms, bedrooms and bathrooms. The lower the score on each item - the ratio of individual wardrobes to residents or the ratio of handbasins to residents - the greater the availability of the amenity. The possible range of scores on this measure is 0-88.

Utilising key issues described by Baker et al[21] in their national study of US community residences I devised a scale to measure participation in Household Responsibilities. Ten items concerned with domestic activities - cleaning bedrooms, preparing meals, doing laundry - were scored on a three-point scale. A score of zero on any item indicated that this was performed by the residents exclusively. The lower the score overall the greater the degree of responsibility assumed by the residents. The possible range of scores on this measure is 0 to 20.

An independence scale was also devised to measure the degree of autonomy permitted to the residents on issues identified as important from discussions with staff. Seven questions are scored on a three-point scale which distinguishes 'all, some or none' of the residents. The lower the score, the greater freedom the residents have to manage their money independently; to depart from, or return to the home at will. The possible range of scores on this measure is 0-14.

The fifth measure used in this study is the Index of Contact with the Community[19] adapted from Campbell. This is designed to ascertain the percentage of residents who had participated in a number of activities, such as shopping, recreation, used public transport or gone on an overnight visit in the last month. Ten items were scored on a five-point scale and summed to give an overall score. The lower the score the greater the number of residents participating. The possible range of scores on this measure is from 0-40.

Measures of the Quality of Care

Data from the five scales measuring dimensions of care were collected to permit comparison of the quality of care provided by each organisation and, within the organisations controlling more than one unit, the variation in care between the units within a common administrative framework. Table 1 shows the scores obtained by the residences on each of the five scales, giving range, mean and standard deviation. Between each organisation and care units within organisations, there are measurable differences in quality of care. The scores on the five scales which were obtained by each unit clearly substantiate this hypothesis. Rank 1 is allotted to the smallest value ie the best. Thus ten units (58.8%) have management patterns which are entirely resident-oriented.

Two of the hypotheses concern the relationship between the quality of care and resident variables. The mean is used to represent the residents' cognitive ability in each care unit.

TABLE ONE

Scales of the Quality of Care - Summary Statistics

		Range	Min	Max	Mean	S D
I	R R M P	24	0	24	4.24	6.57
II	Physical Environment	34	8	42	26.35	10.24
III	Household responsibilities	15	1	16	10.06	4.25
IV	Independence	13	0	13	6.53	3.55
V	Community Contact	29	1	30	12.41	7.42

The number of residents can also be interpreted as an organisation/structural variable in that we wish to examine whether the quality of care is affected by the size of the unit. Four of the indices were strongly associated with the level of resident retardation characterizing the living unit (Table 2). The Index of Community Contact (r_s = 0.4070 was not significantly correlated with mean IQ. More retarded residents received less resident-oriented individual treatment. This supports the findings of McCormick et al[18] and Raynes et al[15]. Similarly the higher the IQ of the residents, the richer the physical environment of the residents, the more responsibility they were given for household tasks and the greater the degree of independence they were permitted. Raynes findings[15] in institutions were similar with regard to physical environment - the less able residents had 'arid' environments, most lacking in physical comfort, and most institutionally-oriented in the way their day-to-day lives were managed.

There is no significant correlation between size or number of residents and any of the measures of caring. Pratt et al[16] had found a significant correlation between size of unit within institutional settings and RRMP scores but noted that size did not affect other dimensions of care.

Correlation analysis shows the relationship between each of the five measures of quality of care (Table 3). The RRMP scale is significantly related to the three scales which describe aspects of the residents' autonomy and freedom from restrictions on a daily basis: Household Responsibility, Independence and Community Contact. It is independent of the Index of the Physical Environment.

Independence is significantly correlated with both Household Responsibility and with Community Contact suggesting a relationship between the scales - the more responsibility residents are permitted (or assume) for domestic tasks, the greater their autonomy. Similarly, their freedom to manage their clothes, money and time is related to the extent to which they seek external social contact in the community.

In support of the findings of Raynes et al[19] in institutional settings, the scale of community contact was not related to the Index of the Physical Environment but was related to the RRMP.

In addition, the higher the quality of the physical environment, the more responsibility the residents were given to perform household tasks exclusive of staff involvement (except for appropriate guidance).

These scales measure dimensions of care which are discreet concepts but analysis of their inter-relationships shows no one scale to be an entirely independent measure of care.

Why were there differences? Why were the units not all

TABLE TWO

Correlations of Measures of Care with Mean Intelligence Quotients

	I R R M P	II Physical Environment	III Household Responsibility	IV Independence	V Community Contact
I Q	R_s = 0.657*	0.720*	0.733*	0.545*	0.407

* Significant at level of $P < 0.05$

S = Using Spearman's Rank Correlation Coefficient

TABLE THREE

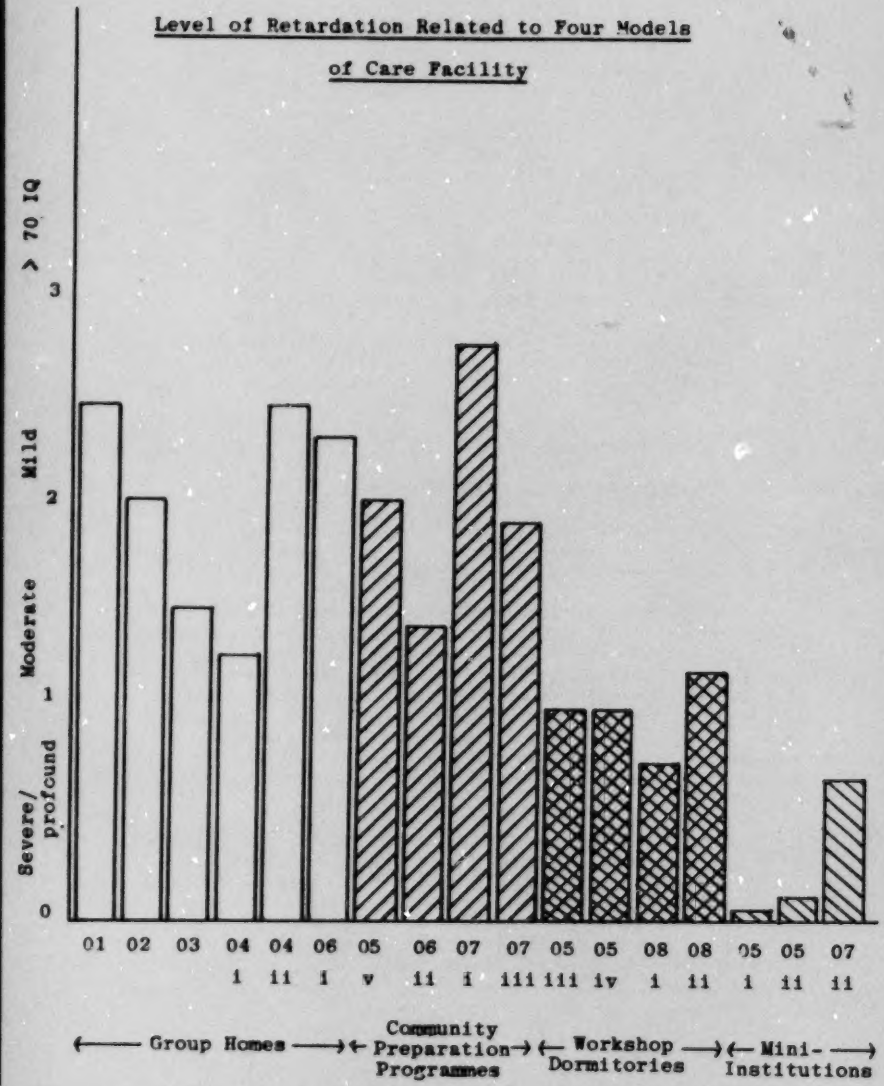
Correlation Matrix of the Measures of Care

		I	II	III	IV	V
R R M P	I	1	0.4833	0.7138*	0.5843*	0.5338*
Physical Environment	II		1	0.5116*	0.3529	0.3229
Household Responsibility	III			1	0.6317	0.3596
Independence	IV				1	0.5122*
Community Contact	V					1

* $P < 0.05$

FIGURE THREE

Level of Retardation Related to Four Models of Care Facility



characterised by resident-oriented care practices on the RRMP scale, for example?

The parent organisations identified the units participating in the study as (a) community-based and (b) alternatives to institutional care. To date they have been described and evaluated as a homogenous group in that they are said to share these characteristics.

Comparison can be made with the categorisation by Baker et al[21] of community residences in the USA by size and by function.

Evidence based on size alone yields little.

It is helpful to follow Baker's alternative approach: to identify potential models of care, to assist in the interpretation of this variance in care practices.

Based on the relationship between the care units and the administrative headquarters, assessment and training units, sheltered workshops and staff input four models can be identified within this study:

- Workshop dormitories
- Community preparation programmes
- Mini-institutions
- Group homes

That the goals of the organisers are translated into action was corroborated by analysis of the levels of retardation, disabilities and behaviour disorders of the mentally retarded adults currently in residence. Figure 3 is adapted from Baker et al[21] and illustrated the mean level of retardation by living unit related to the four models of care facility. The lowest score among units labelled as group homes and community preparation programmes is greater than the highest score of the workshop dormitories. Mini-institutions score lowest both individually and as a group.

Table 4 shows the average scores for the four models related to the five measures of care. On all the scales the workshop-dormitory units and particularly the mini-institutions have higher ('inferior') scores than the other models. There is a statistically significant difference between the scores of the group homes and community preparation programmes on the RRMP compared to the organisation-oriented policy of the mini-institutions.

TABLE FOUR

Average Scores for the Four Models related to the Five Measures of Care

	R R M P	Household Responsibilities	Independence	Community Contact	Physical Environment
*GH	1[1]	9.83	5.33[5]	10.33	17.17
CPP	0.5[2]	4.50[3 4]	4.50[6]	9.50	25.00
WD	4.5	12.00	6.50	12.75	33.75
M-1	15.33	14.67	11.67	20.00	36.67

GH = Group Home

CPP = Community Preparation Program

WD = Workshop Dormitory

M-1 = Mini-Institution

1 Using the t test for the difference between the means of two samples, GM and M-1, t = 3.45 and $0.02 > P > 0.01$

2 for comparison of CCP and M-1, t = 2.98 and $0.05 > P > 0.02$

3 for comparison of CPP and M-1, t = 3.57 and $0.02 > P > 0.01$

4 for comparison of CPP and WD, t = 3.27 and $0.02 > P > 0.01$

5 for comparison of GH and M-1, t = 3.11 and $0.02 > P > 0.01$

6 for comparison of CPP and M-1, t = 4.14 and $0.02 > P > 0.01$

Conclusions and Recommendations

Quality of Care

The four models identified in this study represent alternative methods of delivering residential care in the community to mentally retarded adults.

The quality of care is superior in community preparation programmes and group Homes. These units are characterised by selection of residents of higher ability. On the five dimensions of care examined, all of the indices except the Index of Community Contact were positively associated with the mean level of retardation in each of the seventeen units.

More retarded residents receive less resident-oriented care. Management practices in units with a lower quality of care reflect the organisation of the groups rather than focussing attention on individuals. Value judgements are inherent in the social constructs used in the Revised Resident Management Practices Scale. Where a unit scores poorly on any of the sections: rigidity of routine, block treatment, depersonalisation and social distance, the quality of care will be improved by alteration of the management practices towards resident-oriented care.

The principal recommendations are: -

- the quality of care will be improved by careful attention to the nature of the physical environment for each resident.

- the objectives of care provision in community-based units should be defined.

- admission criteria should be explicit

- increasing care staff involvement in decision-making will assist the development of care programmes associated with orientation towards the individual rather than the group.

- joint assessment of residents' abilities between vocational placement and residential care in the community should be combined with structured training programmes.

Interprofessional rivalry and confusion of roles will be reduced by the use of problem oriented individual care programmes for the mentally handicapped with improved understanding of the complementary way in which nurses and occupational therapists for example, can deploy their skills. Joint education workshops for community mental handicap team members will facilitate this change.

Through analysis of the determining features of care in the community, rational choices can then be made between different ways of organising, staffing and running community based services.

Note

The six scales and additional tables and figures are available from Dr Geoffrey Carroll, District Medical Officer, North East Essex Health Authority, Turner Road, Colchester, CO4 5JT.

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TOWARDS A MORE EFFECTIVE AND INTEGRATED SERVICE

ALAN DAVISON (Chief Administrator, NE Essex Health Authority)

What I want to show before the real experts begin is that there are communication problems amongst all of us as professionals concerned with the care of the mentally handicapped people and these are partly to do with the organisational and technical structures within which we work, but also to do with certain negative and defensive attitudes on the part of us all. And I shall try to illustrate some of my themes.

There are, it seems to me, at least five broad themes here - five major obstacles which hinder all of us in doing our best for mentally handicapped people. Firstly there is the problem of traditional hospital catchment areas for the mentally handicapped. Secondly there are problems in the way in which we collaborate with local authorities which, of course, is of vital importance. Thirdly, ignorance abounds. Fourthly, it seems to me there is an extraordinary lack of data if we want to shift resources from hospital to community, if we want to bring mentally handicapped people out of inappropriate hospitals and fifthly, there is what I call a professional protectionism that works against the interests of the patient or client. I will deal with each of those five points in turn.

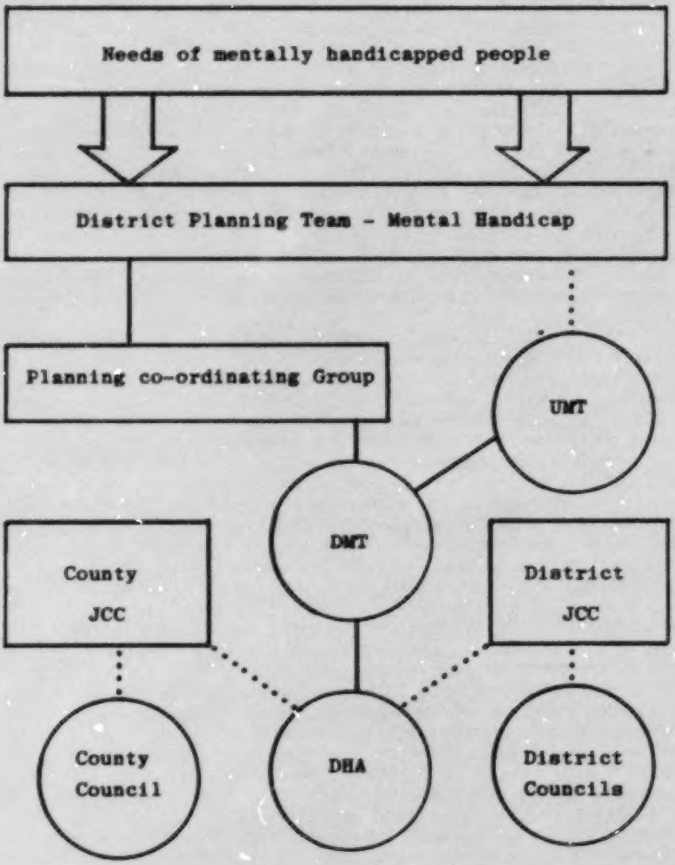
Firstly traditional hospital catchment areas. I should think nearly every one in this room is all too familiar with the problems created by historically placed hospitals for the mentally handicapped and indeed the mentally ill that serve enormous catchment areas and populations, miles and miles away from where that hospital is actually based. The North East Essex Health Authority in which you are situated covers for most services Colchester Borough, Tendring District Council over towards to coast and the northern part of Braintree District Council - two and half local authorities contained within our patch. Now that would be bad enough, but when one adds that in the mental handicap services we are responsible not only for all the people in our normal district health authority boundaries but also responsible for providing mental handicap services to the neighbouring Mid Essex Health Authority and, even worse, to parts of the North West Thames Region. There are moves in this Region to 'rationalise' these catchment areas and the sooner that happens the better. There must be a need to encourage others to pick up their responsibilities and there are discussions about the best way of doing that. It would seem that there is a preference to break up the budgets held by Districts like my own

for mental handicap and mental illness services and to transfer sections of the money to other districts who would then purchase the services provided in the hope that this would encourage them and provide an incentive to build up more local services. But thirty per cent of our Region's mental handicap beds are in this district and eighty per cent of the total Region's mental handicap bed complement is contained within the County of Essex.

Secondly, there are undoubtedly problems over collaboration with our local authorities. You will recall that when the consultative document 'Care in the Community' was sent out various options were put forward, and one of the options put forward and subsequently rejected by the Government was that perhaps we should have responsibility for mental handicap services vested with one Statutory Agency, such as Social Services or the NHS. There was not much enthusiasm for that. Another alternative considered and rejected was that we should invent or establish a single agency with specific responsibility for mental handicap people whether they be in hospital or in community units or in ordinary houses. That too was rejected and so we have a problem with which we have to live. If we look at how the needs of planning for the mentally handicapped people are met we ought to begin with those needs, (Figure 1). The best people to judge those are district planning teams of professionals in conjunction and consultation with voluntary groups, parents' associations, etc. A District Planning Team might be co-ordinated in a typical district health authority by a planning co-ordinating group which would have a responsibility for tying together planning activity over the whole range of services, mental illness, acute services, maternity and so on. But the district planning team for mental handicap would report to the District Management Team. The District Management Team itself has a number of unit management teams and in the case of mental handicap in our own district there is a unit management team consisting of an administrator, nurse and doctor with specific responsibilities for the management and planning - and that is important - of services for the mentally handicapped. Now, the District Management Team is of course accountable to the District Health Authority, and it is at this level that we get into difficulties of formal collaboration. I am not talking about local officer collaboration which generally works reasonably well within planning groups (and that is where the most important part of collaboration is). The District Health Authority has a statutory requirement to liaise formally with County Councils since that is the level at which social services are provided. The mechanism for doing that is by means of Joint Consultative Committees (JCCs). The position in Essex, and in many large Counties, is worsened by the fact that the County of Essex covers no fewer than five District Health Authorities. It is even slightly more complicated than that but I won't bore you with the details and there isn't time. This county JCC is almost the final arbiter on the spending of joint finance funds which are a considerable resource available to mental handicap and other priority services. This begs the question as to what is the sort of mechanism we should have locally. On the right of

Figure 1

Joint Planning in Mental Handicap



the diagram I have shown District Councils. We tend sometimes to forget about those, but they will be of increasing importance as legislation goes through to allow District Health Authorities to make grants directly to housing authorities which at the moment we can't do. And housing authorities are, of course, in the districts and not at county level. So one needs to consider whether one needs a district JCC.

Thirdly, ignorance abounds, inevitably perhaps, regrettably certainly. There is a certain amount of ignorance or misunderstanding, or mistrust amongst you professionals of each other's role. There is a lack of understanding matched by a distance between professionals and so-called decision-makers, or as the local papers are fond of calling us, health chiefs - those who are supposed to take the key strategic planning decisions. There is also ignorance on the part of us decision-makers of the genuine difficulties and problems faced by those of you working directly with mentally handicaped people and providing mental handicap services. Planning within a district will help overcome these communication difficulties. A district management team will look to its unit management team perhaps to form the core of the wider planning group that I mentioned earlier. But that planning group, that group of mental handicap professionals cannot work in a vacuum, cannot work in total isolation and the district management team jointly must agree with them objectives, financial rules and planning guidelines.

The problem is not so serious as far as district health authorities, such as my own, are concerned, where we have very many dedicated enthusiastic professional staff and we are not short of advice. The problem is worse, of course, in those districts where there are no services at all, no hospital services and no local services. Now you may think to one extent that is an advantage and you can actually start from scratch. But without the people and the expertise to help them develop those plans there is a need for very close liaison between our neighbouring health authorities for whom we have a responsibility at present and ourselves. They must be involved in planning teams, mental handicap planning groups whatever you choose to call them.

Fourthly, the problem of lack of data. It is impossible to plan a service and to make such changes that are now going on in mental handicap without better data. I just want to demonstrate this by some of the things that have been happening in my own district health authority recently. We are proposing the closure of Essex Hall, a large hospital for mentally handicapped people. We have issued a consultation document within the last month. As part of the preparation for that document we undertook a survey, not only of the residents in Essex Hall, but of the residents across our district. A survey had been done by the Development Team in 1981 but we wished to repeat that in order to update it. In any case we needed more detailed information about our residents and Figure 2 shows the things that were included in the survey. It follows the pattern of National Development Team

Figure 2

North East Essex District Health Authority Mental Handicap Survey

1 General

2 Original area of residence

3 Contact with relatives

4 Mobility

5 Behaviour problems

6 Continence

7 Medical problems

8 Sensory abilities

9 Self-help

10 Skills

Figure 3

Residents in North East Essex in Regular Contact with Relatives and Area of Residence of relatives

No contacts	300 residents
North East Essex	133 residents
Suffolk	48 residents
West Essex	39 residents
Basildon	38 residents
Other	243 residents
	799 residents

enquiries, with the probable exception 'contact with relatives'. The general part of the questionnaire covered things like, date of birth, sex, date of admission of the patient. We covered original area of residence which coupled perhaps with other factors, might be a relevant factor in deciding whre the best alternative provision for that hospital resident is. Contact with relatives we regarded as important, the degree of contact with relatives, and also importantly where those relatives currently lived. We considered mobility, whether there were any problems of aggression or destructive behaviour, whether there was incontinence - single, double incontinence, how frequent - any specific medical problems such as epilepsy, sensory ability, vision, hearing, speech, we examined self help, whether residents could wash, feed, dress themselves, and finally any particualr skills. As far as just one of those categories is concerned, the third one, the degree of contact with relatives out of our seven hundred and ninety-nine mentally handicapped residents in our hospital care three hundred of them have no contact whatsoever with any relative, or indeed visitor (Figure 3). One hundred and thirty-three of them had contact with relatives who were resident within NE Essex. So there could be said to be four hundred and thirty-three people, who if they were able to be discharged from hospital could be regarded as North East Essex residents since they have no link with any other geographical area. Forty-eight of our residents had contact regularly with relatives who live in Suffolk. Thirty-nine of them have contact with relatives who live in West Essex and thirty-six in Basildon, and the remainder - and it is quite a big remainder - of two hundred and forty-three residents are in contact with relatives scattered over a wide area, so that no particular area had more than thirty or so people. Now that is significant from the point of view of transferring people, because if you transfer a large number of people to a particular area, the transfer of funds which would be necessary and which we would be willing to do is somewhat easier. If you actually transfer two people there is not a significant resource saving within our district to be able to transfer, so imaginative use of joint finance is needed to solve that problem. We looked at the age distribution of our residents, obviously relevant to project death rates and so on and we have, as you can see there, by no means an elderly population (Figure 4). In our district the top line of the histogram shows the age distribution of the entire population in our hospitals, all seven hundred and ninety-nine people. And you can see that the biggest age categories are the thirty-five to the forty-four year old groups. The hatched area at the bottom shows the age structure of those people in Essex Hall.

We looked specifically, admittedly in a subsequent document, in more detail at the breakdown of residents aged sixteen and under and this was done specifically because, as you will know, the government has, in another of its many initiatives, made available a sum of money, not a very large sum admittedly, for bringing mentally handicapped children out of hospital. We are obviously making a bid for that, and I am sure many other authorities are too. The sum available, in the current year that

Number of Residents

North East Essex Health Authority

Mental Handicap Study

Number of Residents in Age Groups from 0-4 to 85-89

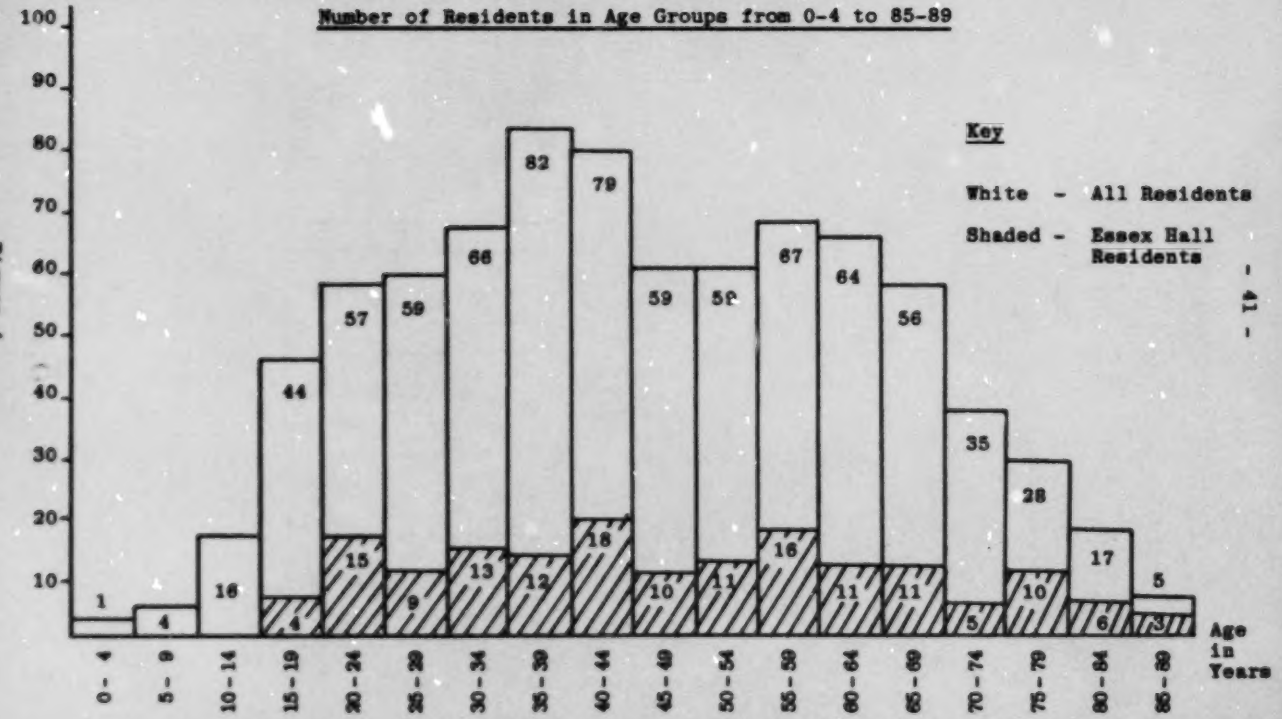


Figure 4

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Figure 5

Children 16 Years and Under

Close Contact with Relatives Resident in Colchester Area,

And No Contact with Relatives

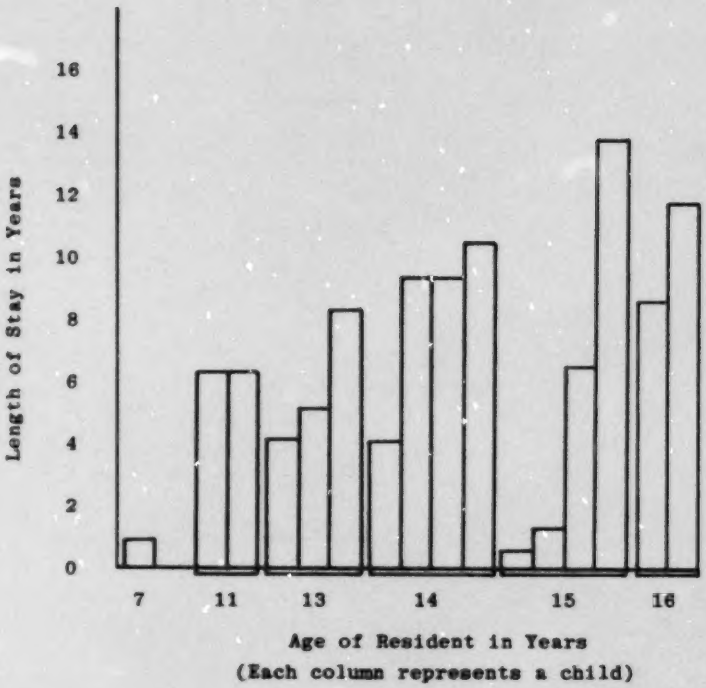


Figure 6

Children 16 Years and Under

Contact with Relatives Resident Outside Colchester Area

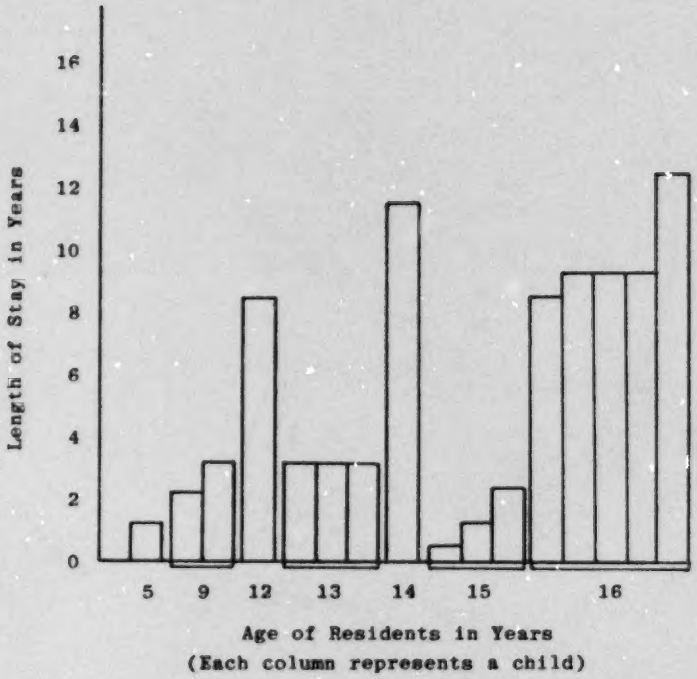
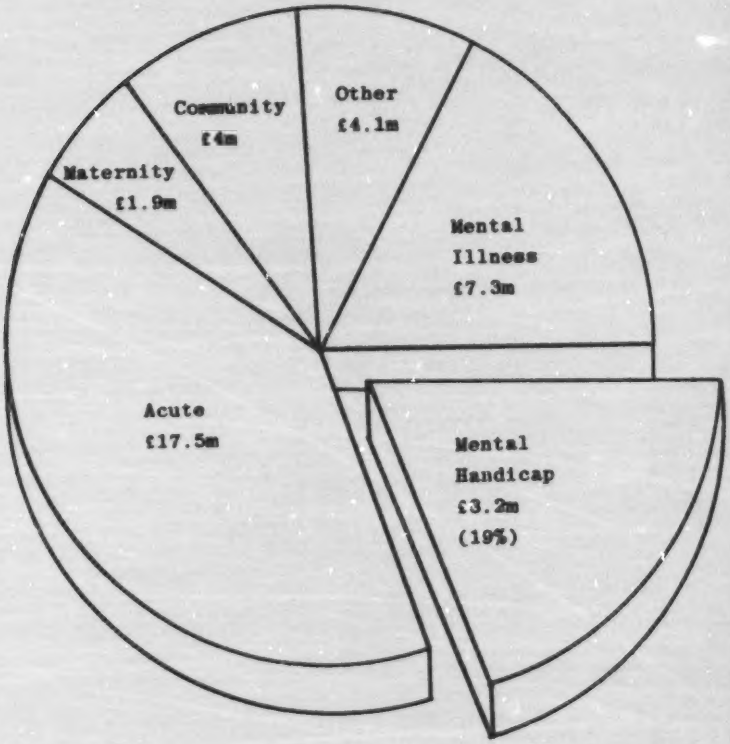


Figure 7

North East Essex

District Health Authority Budgets 1983/84



Total £43m

has just started, is £3m and that would be followed next year and the year after by similar sums. Figure 5 shows the breakdown of our sixteen year olds and below in our NHS care at the moment, who have close contact with relatives resident in the Colchester area or who have no contact at all, in other words those are the ones who if they are to be brought out of hospital should have some form of local alternative provision either in group homes, or hostels, or in ordinary housing in this area. Similarly Figure 6 shows an age breakdown of the other sixteen year olds and below who have contact with relatives outside the Colchester area. Those are the people who we shall be discussing individually with other authorities where relatives actually live.

Lastly I want to move on to what I call professional protectionism and I want to illustrate it with particular reference to the problems of resource allocation and resource use. Let's start with our district health authority budget with is £43m for the current financial year 1983/84 and Figure 7 indicates the way it is divided up. Mental handicap services consume £8.2m which is nineteen percent of our total cake. Now what is interesting here is not the actual size of the cake. Irrespective of the size of the cake in absolute terms what should be the relative division of that cake? Who is to say that mental handicap, given that we have got only £43m in total, should consume nineteen percent of that total? Why shouldn't it be twenty five percent, what shouldn't it be fifteen percent? What is the optimum division of our cake? Now if that is the correct division of our cake then it'll be a chance in a billion. I think it is safe to assume that it is not the best way of dividing the cake. The division of the cake rests upon historical accident and precedent, and we need to be much more objective, scientific and rational about this distribution. Within a unit, such as mental handicap, we can look at three particular functions (Figure 8). What is the best way to divide

Figure 8

Budgets: Selected Functions by Unit (£000s)

Unit Management Team

Function	Acute	Maternity	Mental Illness	Community	Mental Handicap
Nursing	5,100	1,334	3,161	2,084	3,824
Physio	320	3	5	38	15
OT	201	-	197	-	190

resources within a unit amongst the functions and across the professions? In our mental handicap unit at the moment in North East Essex, we are spending £3.8m on nursing, for mental handicap services, £15,000 on physiotherapy, and £190,000 on occupational therapy. That is historical accident and tradition and who knows what the right solution is? What I am concerned about and convinced about is that the best place to have a debate about the optimum distribution within a mental handicap field is not at district management team level but amongst those professionals who are themselves concerned with mentally handicapped people. These professionals should be working together flexibly with a mutual confidence and trust that doesn't always at present exist. Let me just give you one recent example, Mr Chairman, from my own district. There has recently been a large underspending for various reasons we needn't go into on mental handicap nursing amounting to some £100,000. If we continue with functional budgets (that is treating all our budgets as single professional entities such as a nursing budget for the district) it is possible for that £100,000 underspending on nursing to be removed by nursing management and transferred to overcome a nursing overspending in the acute field, or in the psychiatric field. The alternative way of looking at this problem, given that we have made the initial allocation rightly or wrongly to individual units, is to say that that £100,000 underspending on mental handicap nurses should first of all be released, after discussion with one's colleagues, to other needs and priorities within the mental handicap field. And I think that is the right approach and to continue with transfers across a district between units, by so-called functional managers, I think militates against effective and flexible use of resources within a unit. When we tried floating this solution of unit-based budgets and unit management teams the professionals get a little concerned and anxious and I just want to illustrate finally some of the views that have been expressed to me in writing over the last four or five weeks.

> 'There is gross misunderstanding about occupational therapy in the Mental Handicap Division.'
>
> 'Only budgetary management by the district occupational therapist would be able to maintain the standards of the profession.'
>
> 'The present system for the physiotherapy and occupational therapy services should be retained.'
>
> 'For a few disciplines, of which pharmacy is clearly one, such a system is equally clearly inappropriate.'
>
> 'Clinical psychology is not a paramedical service, but a profession in its own right.'

The nurses also expressed defensive views, but they haven't put it in writing. We are therefore in the middle of a very

difficult debate and I don't want to be knocking professionals too much, but we are in a quandary here and it clearly needs to be resolved. I would hope I haven't sounded, Mr Chairman, too negative. Indeed I feel very excited about the changes that are going on in mental handicap and in my own district I feel far more intellectually satisfied, professionally satisfied and much more enthusiastic about the enormous changes that are going on in mental handicap than about any of our other services. But I take your point, Mr Chairman, about professions not competing with one another, or indeed bickering with one another.

To sum up I would say that there are many difficulties faced by staff in mental handicap. You are, all of us here are, undoubtedly hampered by the legacy of hospital catchment areas and frustrated by the complexities of collaboration and joint planning with local authorities. There also needs to be much more information in order to help our rational planning. However, professional staff themselves create unnecessary barriers in my view by their lack of understanding of each other's roles and by their professional defensiveness. The structural and organisational problems we have to live with. We can make them work and the re-organisation of the NHS clearly helps us to do this. There is no excuse, however, in my view for negative, professional self-interest and the best way to break this down is by flexibility between budgets and open discussion between the unit management team and the relevant professions. It is only then that we stand a chance of a better, more effective and integrated service for the benefit of all mentally handicapped people.

Summary

Obstacles to Communication in Mental Handicap Services

1 Traditional catchment areas

2 Problems in collaboration with local authorities

3 Ignorance

4 Lack of data

5 Professional protectionism

MAKATON IN THE 1990'S

MARGARET WALKER (Director, Makaton Vocabulary Development Project, and Research Speech Therapist, Psychiatry of Mental Handicap, St George's Hospital Medical School, University of London)

Surveys carried out over the past five years by the Thomas Coram Research Unit into the use of signing and symbols in schools for children who are mentally handicapped throughout the UK, have shown that the Makaton Vocabulary is extensively used.

THE USE OF THE MAKATON VOCABULARY

From: Signs and Symbols, Thomas Coram Research Unit Surveys, 1978, 1979, 1980, 1982 by Jones, Reid and Kiernan

RESULTS FOR ESN(S) SCHOOLS

	1978	1979	1980	1982
MAKATON	70.3%	81.2%	91.2%	96.0%
PGSS	27.9%	16.0%	4.8%	3.7%
AMERIND			0.3%	
BSL	1.8%	4.0%	2.4%	1.3%
OTHERS			1.3%	
No of samples			330	457
% using signing system	53.1%	90.9%	80.5%	98.9%
Countries in survey		ENGLAND WALES		ENGLAND WALES SCOTLAND

Obviously, these results only cover the special schools' population and therefore do not include any information on the further widespread use of the Makaton Vocabulary in hospitals, like, eg Turner Village; Adult Training Centres; Pre-School Units and in the actual homes of children and adults who are mentally handicapped. Since 1976, thirty thousand people including parents and workers from the caring, teaching and therapeutic professions in mental handicap have attended Makaton Vocabulary Workshops and Training Courses.

Makaton is also being used abroad. It has been used since 1976 in New South Wales, Australia and interest is now growing across that continent. In 1982 the Makaton Vocabulary New Zealand Resource Centre was established and Makaton is steadily being introduced throughout that country. There is also keen interest in the scheme from the United States, Hong Kong, South Africa, Belgium, Norway and Holland.

Why has this happened?

What does Makaton offer mentally handicapped children and adults, their families, teachers and caregivers?

Why has a simple piece of clinical work devised by the author of this paper over ten years ago when she was working as a Speech Therapist in a large Surrey Hospital for the mentally handicapped, been so widely accepted and used?

Let us take a closer look at some of the issues involved -

Let us look first at the communication and language development problems of children and adults who are mentally handicapped, and then let us consider the difficulties that these present for their parents, and to their teachers, speech therapists and caregivers who wish to help them to achieve a quality of life which is appropriate, even if the person is extremely limited in ability. To help achieve this, some means of two way communication whether it be by eg touch, gesture, signs, symbols or speech, is essential. It is well known that children and adults who are described as being mentally handicapped present a wide variety of communication difficulties and language development problems. These vary from individual to individual, in severity and complexity and each person presents a unique combination.

It is possible though to identify, common areas of learning difficulty which affect communication and language development and are well known to most of us. We know, that all learning processes will be affected - if there is a reduction in general awareness and if our perceptual abilities are impaired. This will also apply, if memory is limited and if there is a restriction in the amount of information that can be retained. These problems will not only impose limitations but will delay and impede the development of other abilities dependent of them. For example, the ability to make and form associations and to interpret relationships between people, objects and events will be impaired, as will the ability to store the experiences we have, to classify them, and retrieve them to expand on later experiences.

If these learning problems are applied to the early stages of the development of communication and language then the difficulties we encounter are understandable. Our understanding has been further increased by the information gained in the late 1970s and more recently, from Psycholinguistic Studies of very

early mother-infant communication. These are providing information to describe an activity that has always existed between the mother and infant but was not studied in such detail before. These studies are showing that from birth the infant and mother are constantly engaging in two way, turn taking, reciprocal behaviour involving the most basic forms of human communication, eg through touch, pointing and gesture; vocal play, particularly the use of intonation, stress, and pauses and speech; eye contact and the use of gaze. This is the starting point of communication and language development. It has been shown to be a two way process where each player, ie the mother and infant needs the other, in order to reinforce and stimulate. To begin with, the interaction is entirely wrapped around the mother and infant and the simple routines of caring for a young baby, then gradually as the baby matures, the mother invites and encourages the child to widen his experience to encompass their shared environment. The mother interacts with the child about these new experiences, describing them, repeating and reinforcing them. During this time the mother uses non-verbal and verbal communication which she adapts to match the child's level of understanding and then expands it sensitively to develop her baby's ability. These skills that mothers inherently have, have become known as 'motherese'.

If we relate these studies to the development of communication to children and adults who are mentally handicapped, we realise that the possible implications are considerable and far reaching. The acknowledged learning difficulties which I described earlier, eg reduced general awareness and perception, restricted memory and retention ability, together with delayed maturation of physical milestones, eg sitting, walking, etc have a detrimental effect on the mother-infant interaction, related to the infants degree of handicap. Already there are suggestions that if the mentally handicapped child's interaction with the mother is impaired, then the mother's, (or caregivers), own natural patterns of communicative behaviour within the interaction may alter when she is not reinforced appropriately by the child. Not only then does the mentally handicapped person's communication and language development suffer, but the essential two way communicative interaction between mother (caregiver) and child is also at risk (Cunningham 1983).

So far I have only referred to the development of communication in the young mentally handicapped child, but the possible effects of the lack of or the reduction in experience of this early communicative interaction has equal significance for the older child and adult who is mentally handicapped.

How do parents, caregivers and professional workers attempt to restore what may have been lost, or how do they compensate for what may have been an incomplete experience? Is it possible to identify exactly where and what went wrong and when? Do the current assessment procedures provide adequate detail to indicate what is needed? And are the interpretations being made about

this descriptive data and exploratory research into mother-infant communication sufficiently reliable to be the basis for methods of remediation?

For one moment I would like you to think of some of the children and adults in your care or training. Residents in large hospitals for people who are mentally handicapped, like those in Turner Village Hospital, children and adults like those who visit Project Horizon, children in community schools, adults in ATCs, children and adults living at home. If you think about it then you will agree that their very early communication experience, by nature of their handicaps and circumstances, must cetainly have been impaired.

When I began work on the Makaton Vocabulary in the early 1970s, I obviously did not have access to these studies on mother-infant interaction, since the information did not exist then, but many of the factors emerging now as important influences in the development of communication and language from these studies, seem to me to be within the design of the Makaton Vocabulary language programme, and the combination of signs and speech taught within the structure of the Makaton Vocabulary appears to be unique.

The Makaton Vocabulary (Appendix 1)

The Makaton Vocabulary is a language programme comprising a specific, developmental vocabulary which was designed to provide a controlled method of teaching approximately three hundred and fifty signs from British Sign Language with speech, to mentally handicapped children and adults who have little or no speech and other language handicapped people in order to provide a basic means of communication; to encourage expressive speech wherever possible and to develop understanding of language through the visual medium of the signs and the logical structure of the sign language (Walker 1978).

It was not part of a large scale research project, but resulted from a response to a clinical need in a working environment. The original vocabulary was devised in 1972, as a project to teach sign language to deaf mentally handicapped adults (Walker 1977). It was revised in 1976, to meet the needs of mentally handicapped children living in the community as well, and it is this version which is currently in use.

The Structure of the Makaton Vocabulary

When I was contemplating the use of signing with speech to encourage communication in mentally handicapped people, I was excited by what looked like a possible breakthrough with the use of the signs, but I felt strongly that the signs and speech should be introduced in an organised manner, and that a structured vocabulary was the possible answer. Mothers of young

children, although they introduce vocabulary that is specific and meaningful for their own family and the individual child, still express basic needs and early communication within a fairly restricted narrow vocabulary (Armfield 1982), so I decided deliberately to devise a limited restricted vocabulary.

Points that Influenced its Design

1 It should be a 'core' vocabulary of heavy duty words, simple to learn and basic for early communication.

2 It should be deliberately limited in size to keep memory loading and retention light.

3 Words/signs chosen should wherever possible be multi-functional and should combine together, so that phrases and small sentences could be formed from words used earlier as single words, again reducing memory loading.

4 The vocabulary should be presented in a developmental sequence, so that easy concepts are presented first and more difficult ones later. This would enable a handicapped person to work through the vocabulary as far as their ability allowed them.

Recently it has been suggested that mentally handicapped children's language acquisition does not follow normal development. In view of their impaired early communicative interaction might it not be that these observational studies are showing effects of this and that remediation should adhere to normal development to provide a goal?

5 The two-way functional communication process was built implicitly into the scheme, so that each stage contained vocabulary not only for the handicapped person but reciprocal and facilitating signs/words for their partner(s) to use to permit a two way communication activity to develop and be enjoyed, eg what? where? yes? no? This was essential, since no one communicates alone.

Recently psycholinguistic theory has been applied to the design of the Makaton Vocabulary Language Programme (Armfield 1982) and the vocabulary is shown to contain almost all the psycholinguistic features of early mother-infant interaction.

6 Another reason for using a defined 'core' vocabulary was to provide a framework against which targets could be set and progress could be charted.

7 Consideration of individual personal needs is allowed for by being able to introduce additional essential vocabulary into any appropriate stage of the vocabulary and by being able to choose within each stage the sequence of signs to be introduced or taught within that stage. The signs do not have to be taught straight through down the list for each stage as printed, and

signs/words not appropriate or outside a person's experience, eg 'nurse and doctor' for a child living at home and attending community school may be omitted.

Whilst it may seem more appropriate to design a vocabulary around a handicapped person's own personal communication needs to increase motivation, it is difficult to do this in practice. The risk of inconsistent use and the difficulty in managing to remember individual differences for workers caring for groups of handicapped people, when individual vocabularies are used outside a one to one or narrow environment is very great. It may be better to accept a small compromise and offer a standard 'core' vocabulary which suits more general needs of a group and which can be more generally learnt and consistently used.

Teaching Methods

Specific teaching approaches are recommended and the vocabulary stages of signs/words should be taught in:

1 a structured formal manner to handicapped people so that they will be able to gain maximum comprehenison and encouragement to use the sign/words in functional communication and then signs taught must be used in:

2 an informal manner to generalise use

Each stage should be taught in sequence and adherence to the vocabulary within stages is recommended with the exception of the introduction of additional vocabulary items.

Running parallel with the teaching of single vocabulary items should be the opportunity for the child/adult to experience the use of the same signs that they have learnt as single items in small meaningful phrases and sentences. This vocabulary expansion into other language forms is taught and encouraged, right from stage one- the simple beginnings of the vocabulary.

The Project's Training Committee and Regional Representatives network is continually monitoring, refining and reseaching with different teaching approaches to suit individual and group needs. Details of these are available by attending Makaton Vocabulary Workshops and Training Courses.

Signs Used

Sign Language is the cultural language of the deaf community and it should be regarded as a full language with its own grammar, syntax and dialects as we regard, eg French or Russian as unique languages. It does not follow spoken word order, since it is not a translation of spoken language but a language in its own right. Sign Language was not devised by anyone; it evolved through sign use by the deaf themselves over centuries, in the

same way as spoken language has through usage.

Prelingually deaf people all over the world will use Sign Language so there is eg British Sign Language (BSL); American Sign Language (ASL); French Sign Language (FSL); etc. Cultural differences occur between countries, but the underlying structure is similar.

Facial expression, appropriate to body language, gesture and mime also feature a great deal with Sign Language and are an essential part of the communication. There are not strict rules as regards the precise performance of the signs, eg the actual size of the sign or the distance from the body. These details are dictated by the needs of the message to be conveyed. This flexibility is a great advantage for handicapped people. Also the ideographic nature of many of the signs conveys meanings easily.

Signing English is a systematised attempt by hearing and deaf people to provide a linguistic signing equivalent to spoken language. Sometimes signs are combined with finger spelling and speech and in some Signed English teaching programmes, the objective is to be able to provide a sign vocabulary representing all the components of spoken language.

The Makaton Vocabulary assumes a midway position. It uses key signs from the Sign Language of the Deaf and utilises some of the performance features, eg facial expression, body language, use of placement, directionality, etc. It presents these key signs in spoken word order so that it provides a Signed English framework. Thus if a handicapped person is successful on Makaton and continues to have a high dependence on signing he/she can progress to a fuller Signed English programme. The tendency to favour Signed English rather that a British Sign Language framework was no reflection on one being more superior to the other, but because the objective of a Makaton Vocabulary programme is to encourage speech and therefore signs presented in spoken word order seem more appropriate.

Throughout the UK the south east/London dialect is used with the system. It was necessary to standardise the dialect to reduce confusion for the intellectually handicapped people using the scheme.

The Use of the Makaton Vocabulary (Walker and Armfield 1981)

The 1976 Revised Makaton Vocabulary is now in use with:

1 Mentally handicapped deaf and non-deaf children and adults who have little or nor expressive speech and poor comprehension. Makaton may be used across the entire age and intellectual range. Research is now showing the effective use of Makaton with young Down's babies (Le Prevost 1983)

2 Children and adults who are both mentally and physically handicapped

3 Those considered to be autistic

4 Some young deaf children in the ordinary range of intelligence

5 Children with severe articulation or speech rhythm problems who need a temporary alternative

6 Certain normal adults with acquired communication problems

More recently Makaton has been reported to be of value with two more handicapped groups:

7 Blind and partial sighted children and adults

8 With psychiatric cases where language and communication is impaired

Experience has shown that in addition to the development of concepts and language other positive results can occur. These are reported to be increased:

- eye contact
- attention
- sociability
- vocalisation, and
- expressive speech.

A marked reduction in inappropriate behaviour is also reported. For those with severe communication impairments, signing can stimulate rather than interfere with language development. These positive side effects fall into a pattern that cannot be easily explained but do raise questions about the use of attention focussing devices as they relate to concept development and the contribution that a communication priority system such as Makaton can make to general language development.

Those who teach and use the system include speech therapists, teachers, occupational therapists, psychologists, parents, instructors, and social and/or hospital staff. They are provided with training in One Day Workshops.

The Makaton Vocabulary Development Project (MVDP) (Appendix 2)

Like the Makaton Vocabulary itself the MVDP grew from a need. In this case the need to support and offer a service to parents, and workers using the Makaton Vocabulary with children

and adults who are handicapped.

It is a non-profit making organisation, which has very recently become Charity. It has always operated on slender financial means with a tremendous voluntary contribution being made by the Project Co-Ordinator, Training and Research Committee Members, and Regional Representatives. Through the MVDP, Workshops, Training Courses, lectures, related publications and teaching material are provided.

The Training Committee and Regional Representatives network are continuously monitoring current training methods and new ideas and approaches. There are three signing advisors on the Training Committee, who work regularly with the deaf community. Their role is to advise on the use and maintenance of signing standards of the Regional Representatives and within the MVDP Training Courses. The Research Committee also acts in a monitoring capacity. Arising from the need to keep the MVDP Regional Representatives, who are all practitioners, in touch with research, has been the production, since 1980, of the MVDP Research Information Service. This provides practitioners with detailed information, which is continuously updated, of all related research projects. A summary of each paper, indicating clinical and educational application is given. This Service is issued as a publication to anyone wishing to purchase it from the MVDP. Current and future projects involve:

- an evaluation of the use of symbols with Makaton;

- an investigation into the value and use of the Makaton Vocabulary as an aid to teaching reading;

- an evaluation of current assessment procedures and their appropriateness to non-speech systems;

- the establishment of a data bank to collect information via the Regional Representatives network into the language acquisition of handicapped people and the most effective teaching methods;

- the establishment of national parent groups linked to Regional Representatives to provide exchange of information and needs.

The address is:

MAKATON VOCABULARY DEVELOPMENT PROJECT
31 Firwood Drive, Camberley, Surrey
Project Tel: Camberley (0276) 61390
Admin Secretary: Farnborough (0252) 513607

Summary - What Makes Makaton so Effective? (Walker and Armfield 1981)

Some observations on the Makaton system can be made:

1 Makaton appears to be the only alternative communication system which has been divided into 'developmental stages'. Other lexicons have been studied and/or prepared, but Makaton provides a set of lexicons organised in stages which are increasingly complex.

2 The vocabulary provides a guide for even the most experienced language development teacher or therapist - as well as for those new to vocabulary development - to deciding on priorities in developing communication and it also offers a guide to planning and measuring progress. The stages suggest a realistic and economic limit on vocabulary instruction attempted in a sequence for children with very limited abilities, while the freedom of choice within the stages allows for as much creative judgement as the instructor wishes.

3 The range of vocabulary has been carefully chosen so that as the concepts are learned they can be used to connect and combine into two or three words sentences and longer. This design feature is present from the earliest stage and throughout the entire vocabulary.

4 A source of frustration for many who wish to explore sign language as an alternative means of communication is that initial training requires weeks of study before an adequate vocabulary is acquired. This is not so with the Makaton Vocabulary because the graded stages permit communication to begin immediately at the most basic level.

5 It is a potential guide for using alternative communication systems other than BSL for persons with severe communication impairment. Symbol, picture and other alternative communication systems usually rely solely on the judgement of the teacher/therapist for selection of the vocabulary to be taught. Makaton provides a guide for selecting vocabulary - especially initial vocabulary.

6 Because the system is widely used throughout the United Kingdom, it offers an exceptional opportunity for collecting data on the language development of persons with severe communication impairment. Extensive data gathering could provide information pertinent to learning more about the teaching and acquisition of normal language development.

Finally, the growth of the Makaton Vocabulary has been very rapid and we have in this country now a situation where clinical practice has raced ahead of research practice. It is therefore not surprising that there should be some criticism. It would be unhealthy had there not been any.

We must look realistically at this current position. Practitioners, eg teachers, speech therapists, nurses, and parents, are intensely aware that time and early intervention are of the greatest importance to try to improve the quality of life for children and adults who are mentally handicapped and with whom they are closely involved. They cannot therefore easily accept that they must wait for substantial and detailed research to be completed. Also the detail and quality of research data required has not been started yet and would involve the pooling of financial and professional resources.

Could I therefore make an appeal for a closer working relationship between Researchers and Practitioners, and a greater mutual respect for the contribution that each may offer the other and ultimately the handicapped child or adult.

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THE DEVELOPMENT OF COMMUNICATION SKILLS: WHERE SHOULD WE GO NEXT?

CHRIS KIERNAN (Deputy Director, Thomas Coram Research Unit, University of London Institute of Education)*

Introduction

In this paper I will try, very briefly, to outline what I see as the sensible directions for work on the development of communication skills by individuals with severe communication problems. I will take a fairly broad perspective both in terms of groups covered and in time. By adopting this approach I hope that various guidelines for future planning of research and practice may emerge.

I will make several assumptions in what follows. These are: (a) That the population to be considered is heterogeneous, including both mentally and physically handicapped children and adults, and adults who have suffered strokes or experienced surgery which has affected their ability to speak. (b) The second assumption is that communication through speech, synthetic speech, or writing using traditional orthography, will be the ultimate aim of any remedial programme. I will therefore assume an interest in speech and the development of early communication skills. The use of sign languages, or symbol systems such as Blissymbolics or rebus, will be seen as a step toward the use of speech. The rapid development of inexpensive general purpose microprocessors of increasing sophistication which can be linked to assistive devices which synthesise speech holds great promise and suggests that all individuals may, in the future, be able to use at least this form of communication. (c) There is a need to look at both short-term and long-term goals. In the short run we must consider how what we already know about communication and about the use of various augmentative systems can become embodied in practice on a wide scale. However we also have to be researching and planning for service developments which may not be practicable in the short-run.

The Current Scene

Research and development relevent to the needs of individuals with severe communication problems has progressed markedly in the last fifteen years. In particular there is now a

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substantial body of literature on normal child development which has implications for the planning of remedial schemes and interventions. This literature reflects changing concepts of language development. Prehistoric views of acquisition, cast in terms of vocabulary development, have been replaced by an appreciation of the need to analyse syntactic development, the development of embodiment of meaning (semantics) and the development of language as a tool of social interaction (pragmatics). These three lines of work intertwine to present a complex framework within which we should consider therapy and intervention.

Literature on normal language development offers exciting promise. However, there are two problems. Firstly, many of the implications of this work have not been drawn out. Secondly, much of the work is inaccessible to practitioners. Some work is frankly obscure, but even where readable texts are available practitioners may find them either difficult to digest or difficult to translate into practical terms.

The net results are that clients are missing out on the potential benefits accruing from research and that the position is getting progressively worse. The cut-backs in provision of in-service training are exacerbating the position.

The development of augmentative systems, sign and symbol systems, has been largely practitioner led. Beginning in the late 1960s the use of sign and symbol systems has become increasingly common. Spread of systems has, in the main, followed personal recommendation. Choice of systems for institutions, choice for individual children, teaching methods and methods of evaluation fail to reflect any appreciable impact of theory or research on normal child development or of research on augmentative systems (Kiernan, Reid and Jones 1982). There is very little evidence of consideration of the use of microprocessors technology in the UK.

Experience and research during the last decade suggests that many individuals in all of the groups considered can be helped toward independence through teaching using even the crude methods so far evolved. The commonest sign system is use in schools in the UK is the Makaton Vocabulary. The majority of schools for the ESN(S) use this system (Reid, Jones and Kiernan 1983). other sign systems, specifically the Paget Gorman Sign System and Amerind, are used with adult populations but we have no estimates of frequency of use. The commonest symbol system in terms of numbers of schools using a system in Blissymbolics. However in a recent survey we found that in terms of numbers of children being taught to use 'Rebus systems' were more commonly employed (Reid, Jones and Kiernan 1983). We do not know exactly what schools mean by 'Rebus systems' beyond the likelihood that such systems are more pictorial than Blissymbolics. Furthermore we have no estimates of use of symbol systems by adults.

Although relevant research on the use of augmentative

systems with handicapped populations in the United States is extensive research in the UK is sparse (Kiernan, Reid and Jones 1983). Similarly, development projects concerning various types of schemes or equipment are relatively common in the US but rare and, to my knowledge, poorly funded in the UK.

Areas for Research and Development

The remaining part of this paper will be divided into two sub-sections. The first part will suggest what ideally could be done in terms of research and development. The second part will offer some suggestions on specific short and long-term objectives.

1 What Could be Done?

We can usefully divide our discussion here into themes concerning the use of systems at a general level and themes relating to teaching method.

The Use of Systems

1.1 Although we know a good deal about who is using what system at the special school level (with the notable exception of schools for the deaf), (Jones, Reid and Kiernan 1982; Kiernan, Reid and Jones 1983; Reid, Jones and Kiernan 1983) we do not know what relevant staff in pre-school facilities are using and nor do we know what is being used by language units in normal schools or in adult facilities served by Health or Social Services. We know little of the range and quality of support and advisory services and so can not estimate resource needs.

1.2 A range of questions can be asked about the users of systems. We have a gross idea of the likelihood of success of users in relation to different types of system for those systems currently in use (Kiernan, Reid and Jones 1982). However we could pursue the aim of further refinement of criteria for use of systems. Work on the development of assessment procedures is currently being funded by the DHSS at TORU.

We know very little about the outcome of use of the various augmentative systems, or of the outcome of speech-based programmes, in terms of variables derived from contemporary work on language and communication or outcome in terms of general cognitive development. Our ideas on the extent and reasons for speech development within programmes using augmentative systems are sketchy and relatively crude. We know virtually nothing about user acceptability and yet this is likely to be a crucial variable affecting use.

1.3 As indicated in the introduction, a variety of microprocessor based systems are being developed. To date there

seems to be little or no information on the impact of these systems on the development of communication, language and cognition. And yet, looking to the future, questions will clearly be raised concerning the especial merits of, for example, synthesised speech over signing or symbol use as it affect normal speech development and other aspects of development.

1.4 The impact of environmental factors, or what are referred to these days as ecological factors, can be approached at several levels. Acquisition of speech, or use of an augmentative system, can be studied within naturally occurring one to one settings, such as the parent-child dyad, or those occasioned by day-centre or hospital settings. Information from such studies could illuminate where success and failure was occurring, especially if comparison with data from normally developing children were also gathered. Studies also could examine the impact of physical environment as it sets the stage for interaction and the evolution of communication. We can hypothesise that some environments, for example traditional hospital wards, will provide minimal occasion for communication and thereby for learning or use of speech or augmentative systems. Similarly the social organisational structure of environments could be examined. It seems likely that the use of augmentative systems, in particular, will be affected by the degree to which staff share goals in their use within settings. This consideration relates to two further questions. Generalisation of use of augmentative systems is a persistent problem for teachers and therapists. Explanations for failure of generalisation almost certainly relate in part to organisational factors, although user and physical environment variables are probably involved also. The other question concerns the acceptability of systems to staff, parents and relatives. Acceptability of materials and instruction, the perceived image of the systems and perceived difficulty of systems, have all been shown to relate to adoption and use of systems (Kiernan, Reid and Jones 1983). Other factors probably relate to more subtle variables such as the extent to which use of the system 'fits' with normal interaction in terms of rate of transmission of information and the possibility for inclusion of paralinguistic information along with specific messages.

Methods of Teaching

We have scant information on current teaching methods. What we know about the methods being used suggests that they are limited, and the examination of current practice would be difficult methodologically and would yield little valuable guidance.

There are several lines of work suggested by current needs.

1.5 Investigation of methods of assessing and teaching syntactic, semantic and pragmatic aspects of language and communication This 'line' clearly subsumes a vast range of

possible projects, all with clear applications, and all suggesting the use of a variety of investigations using differing methods, including intervention. One approach would involve research which could explore the parallels and differences between normal and handicapped individuals along dimensions derived from current theory and research (cf Bloom and Lahey 1978; Kiernan 1982; McLean and Snyder-McLean 1978).

1.6 I have suggested that the eventual outcome of therapy should be seen as the development of speech. We know relatively little about the factors which lead to speech development within programmes using augmentative systems. This should be a priority area for research.

1.7 It is quite likely that different systems have different prime benefits. In particular symbol systems may lend themselves to the teaching of syntax (Kiernan 1983). We could investigate this and the related question of 'reading' instruction or language or cognitive development.

1.8 We noted in discussion of the current scene a failure to translate research findings into practice. This failure is crucial because it deprives potential clients of the benefits of research and because research workers and theoreticians need feedback in order to clarify and guide their work in such a way that it remains relevant.

We have no information on systematic Health Service or Local Authority based in-service training programmes which would lead to the implementation of new ideas or lead to improvement in teaching method. We are developing an in-service course (Foundations of Communication and Language, Kiernan and Reid 1979, 1983) in conjunction with the British Institute of Mental Handicap, which is designed as an 'enabling' package through which new ideas and information can be introduced to relevant practitioners in a practical context.

Our current, informal, evaluation suggests that the course meets some felt needs. Other courses are, we understand, being planned by the Spastics Society. Given the need there is clearly room for a broad spectrum of in-service courses.

2 Short and Long Term Objectives

From the range of areas indicated we can select a series of objectives. Clearly there will be differences of opinion in priority areas. Those offered here reflect my own biases and experience. Short term objectives would, for me, include the continued, and extended, monitoring of the types of programmes and systems used. This seems a sensible basis for planning. Related to this could be a monitoring of support in terms of effectiveness. The other prime short-term objective should, in my view, be the development of in-service training.

My long-term objectives reflect the belief that the use of speech as a means of communication should be the ultimate goal of any intervention. I would suggest that augmentative systems should be seen as teaching aids. From this follows an urgent need to investigate the use of such systems in potentiating speech development. Although we have many hints as to mechanisms we really know little about how to use augmentative systems in this way. Still on the research side, and related to this topic, is the need to investigate factors underlying generalisation of communication skills.

Finally, as I mentioned in the Introduction, the development of inexpensive general purpose microprocessors offers a unique opportunity to apply technology to the needs of the handicapped. We have scarcely begun the exploration of the benefits of these devices. Of particular long term interest is the use of speech synthesis both as a means of giving handicapped people 'voices' and as teaching devices to encourage speech.

The communication needs of the more severely impaired were, for many years, sorely neglected. Much has happened during the last decade to help them. We need both short and long term planning and research to capitalise on these advances.

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COMMUNICATION DIFFICULTIES AND VISUALLY HANDICAPPED PEOPLE

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Preverbal Communication

Language was once assumed to 'arrive' eighteen months or so after birth. During the last ten years or so, however, evidence has been accumulating of the central importance of pre-verbal communication patterns established between child and parent during the first year of life, as part of a social interactive process (Schaffer 1977). The infant can now be seen as behaving in a relatively organised way rather than subject to the primitive chaos which was once assumed to reign. The mother takes part in this social development by fitting her behaviour into the existing patterns of activity displayed by the infant.

During the first year of life the infant learns that his interactions with another person are two-way affairs. The dialogue between them involves reciprocity including skills like waiting, listening, watching, copying and replying, and intentionality or the realisation by the child that his behaviour can be used to influence the behaviour of people and objects around him, with desired results. In other words the child acts in order to bring about particular goals or ends. In this sense crying may be simply a response to pain but it could also be a means of bringing mother to him to deal with the cause of the problem. In the latter case crying has a clear communication role.

The infant will learn by experience that his smiles, nods, vocal noises, gestures and movements are responded to by others and can bring particular effects. Schaffer (1977) suggests that the remaining important ingredient, in addition to the child's developing abilities to interact, is opportunity or the regular presence of another person to interact with, and this is usually provided by the mother. A broadly similar formulation of the preverbal communication process is offered by Newson (1978), who offers three guidelines:

> 1) each participant must have a repertoire of distinguishable actions which can function as 'signals'.
>
> 2) each individual must be sensitive to the display of such signals by the other individual, and be prepared to give up his/her own activity in order to

attend to that being displayed by the other.

3) participants in the communication must develop an understanding of the need to sequence and inter-relate their activities to allow a pattern of exchange to take place between them.

The interested reader can explore the detailed discussions of preverbal communication characteristics in texts such as Schaffer (1977) and Lock (1978). For present purposes, however it is useful to summarise the discussions of two or three aspects offered by contributors to the field in order to indicate the central relevance of vision to the early communication process.

Imitation and Turn-Taking

Pawlby (1977) has described how, from an early age, mothers and infants co-ordinate their interactions and adjust their behaviour in response to the behaviour of the other partner. There is a pattern of alternation between the partners while interacting, which has been described as a kind of 'conversation'. Each action in this turn-taking routine might be understood best as a kind of communication gesture. Imitation is one form of this 'communication' routine where one partner reproduces the act just displayed by the other partner. Some of the activities noted by Pawlby as examples of imitation between parents and children are listed below. Those marked by an asterisk include the use of vision.

* smiles
  blowing 'raspberries'
* mouth movements (purses lips)
  laughing
* tongue-poking
* frowns
  voice pitch/tone
  sighs
* eyebrow movements
  tongue-clicking
* eye pointing/staring
* arm/leg movements
* 'peep-bo'
  coughs
* claps, bangs (with hand)
* hand games
* 'giving' object
* uncovering objects
  smacking lips
* head shaking
* nodding
* waves

Turn-taking is an essential part of imitation as one partner copies the action of the other; but it often occurs through a longer sequence of turns or 'replies' between partners. In the early months of a child's development a mother is most likely to follow the action of her child, but as the child grows older the frequency of imitations he/she makes of the parents' actions increases. Imitation seems to be a means of building a shared understanding of actions and events between mother and child. If so it suggests that meaning is socially constructed at a very early age, well before speech appears. Mothers appear to initiate imitation routines almost from the time of birth by copying certain movements and gestures made by the child. In particular though, studies suggest that mothers tend to select

gestures which have some value in communication.

Visual Co-orientation and Objects

After a few months of life objects tend to compete more and more with people for an infant's attention. To engage in social contact with a child an adult must take notice of, and use, an infant's interest in objects. One study (Collis and Schaffer 1975) showed that mother and infant eye-gaze was usually directed to the same object or toy at the same time, mainly because the mother followed her baby's direction of gaze (rather than vice versa). Mothers would then often go on to name the object and comment upon it. Mothers tend, also to interpret the actions and interests of their children towards objects by eg, referring to, and requesting or providing extra information about the object in focus.

Infants may also follow the gaze direction of adults. One estimate suggested that this ability may emerge reliably at around nine months. Using this skill the infant can benefit by relating mother's verbal comments about an object, to the object at which she is looking.

Visual Loss and Early Development

Blindness produces a number of delays in the development of basic skills during the early infant period, including mobility and visually guided reaching; meanwhile reaching for objects on sound cue emerges at roughly the same age for blind or sighted infants (eight to nine months) (Unwin 1977) by which time many of the blindness-related delays have already made their appearance. The sighted infant can initiate social interactions with parents simply by looking at them. Mother or father tend to mould and shape their own movements in response to those of the infant. They will give meaning to many infant movements and gestures by the ways they respond to them, providing verbal labels, copying certain movements or showing pleasure. Much of this feedback from parents is received visually by the infant.

Blindness in a young child serves to deprive the parents of many of the rewards normally provided by a sighted child's activities. The blind baby does not return their eye-gaze, does not smile readily without encouragement and does not engage in the various forms of exploration or visual searching which, in a sighted child provide parents with opportunities to join in and help create and maintain the activity.

The socially derived patterns of preverbal communication which are built up between adult and infant during the first year or so of life depend in large part on the development of reciprocal recognition of objects and activities. Consequently, this development depends to a large degree on visual skills in both participants.

While reciprocity of experience and meaning can be developed without sight, it must be worked for consciously under such circumstances, by making careful use of non-visual cues through sound, touch, taste and smell. The implication to be drawn here is the need to provide help and guidance to parents in how to make use of non-visual cues in place of the preferred visual ones.

Sally Rogow (1980) notes the need to establish an alternative signalling system for the blind child, using words, sounds and motor actions to convey meaning. Teaching a blind child that holding out his/her arms will get him/her picked up by his parent, will give the child access to social contact and the parent a sign about the child's needs that he/she can interpret reliably. Rogow describes a routine of 'co-active intervention' by which such communication can be set up. It requires:

1) a system of consistent and clearly defined responses to the child's behaviour,

2) a system of signals based on the interests of the child,

3) use of a variety of objects and experiences to establish the child's interests,

4) stress on mutual actions and reciprocal interchanges, and

5) enjoyment of the child's response to the adult.

It is often easier to encourage the child to make a signal and obtain an enjoyable response from the adult, than to expect the child to learn and respond to signals from the adult. Clearly defined gestures such as hand-clapping, or gestures based on actions used with objects serve well as signals. The involvement of objects in the parent/child interaction is vital to give meaning to the words which will be used to identify them, first by the parent and more importantly, later by the child. Blind children find it easy to imitate words they hear around them (a source of experience which does not depend on vision) but their use of such words will be meaningless unless they experience directly the objects and activities to which the words refer. Echolalia is a not uncommon consequence of passive listening to speech by blind children.

The consequences of inappropriate early communication and social experiences in blind infants is all too obvious in the developmental norms published by Joan Reynell (1978). These suggest that the verbal comprehension of blind children is delayed by six to eight months at two years old compared to sighted children, and is beginning to slow by comparison with that of partially sighted children at this age. By age five blind children show a delay in verbal comprehension of one year or more. Expressive language skills are also subject to delay in

blind children. Interestingly however, blind children perform better than their partially sighted counterparts during the 'jargon' stage (around one to two years old) but fall behind again when words begin to be used as true object labels. Sighted children have a six to eight month advantage over blind children from age one onwards in terms of expressive language structure *while the gap is even larger* (eighteen months ahead) in terms of language content.

Mental Handicap

The limitations on language development among mentally handicapped people is well known and does not need to be elaborated here. The presence of a visual handicap increases the developmental problem considerably. If a child has both impairments he/she will need very special help if delays in language developemnt are to be minimised. The major risk, however, must be that the language delay will be assumed to be inevitable if the child is thought to be mentally handicapped, and that less effort will be made to ameliorate the delay. The risk can be compounded by shortcomings in many current methods of assessing visual function in young children (viz Atkinson and Braddick 1979), and intellectual level in blind poeple (viz Ellis 1978; Langley 1979). The numbers of specialist assessors able to carry out such evaluations appear to be relatively limited. Additional problems may be likely to arise for clients who suffer some degree of mental retardation if ophthalmic specialists assume that such clients will be unable to cope with corrective surgery or with visual aids such as spectacles. Consider, for example the results of a study by Bader and Woodruff (1980) of the effects of corrective lenses on the behaviour of a group of mentally retarded people. They report improvements in social behaviour, gross and fine motor skills, and reading and writing skills. These changes were most evident in the youngest (nought to six years) age group.

Of particular concern in relation to such problems is the remarkably large proportion of mentally handicapped people in the UK who are known to suffer some degree of visual impairment. Ellis (1982) reported results of a national survey of visual and mental handicaps in our institutionalised population which suggested that about ten per cent of institutional residents were either blind or partially sighted. The reader might be tempted to assume that visually handicapped people are more likely to drift into institutions, but a survey of children in ESN(S) schools in the Manchester community (Mittler and Preddy 1981) revealed that about fifteen per cent had some degree of visual handicap. These prevalence rates are ten times larger than the prevalence of visual handicap in the general population (viz Cullinan 1977). The national survey of institutional residents also found that the proportion of blind children up to sixteen years old was about three times larger than sighted children.

Blind residents were found to be generally more dependent

than their partially sighted contemporaries in self-care skills like washing, feeding, dressing and toileting, while only about one third of blind inmates could speak adequately. In addition, over forty per cent of blind residents had no form of occupation or training at all. These findings raise the question, to what extent such dependency is due to visual impairment rather than to mental handicap? It has been argued elsewhere (Ellis 1983) that such problems and needs can be met adequately only by the establishment of more specialised living and training units in institutions and by the recruitment of appropriate training of specialist staff.

Physical Environment and Communication

Specialisation of living resources for visually handicapped people requires attention to a number of physical features. These have been described by Best (1983) and have considerable relevance to many communication-related needs of visually and mentally handicapped people. In this context 'communication' is used in the broadest sense, to include non-human sources of information available to the blind resident.

Sound sources are an important source of information for the visually handicapped person. The spoken word is eagerly awaited even by blind people who cannot speak themselves. Staff and other sighted residents can convey information in this way to a blind person that cannot be accessed by any other means. 'What time is it?', 'What is happening outside via the window?', 'Where are we going?', 'Who is this new person?' Sounds can be non-human also and convey information about the approach of others (footsteps) about sources of danger (car engines; the whine of an electric wheelchair) and, perhaps less obviously about the size of the room. But many factors impair the supply of this information. Most wards in mental handicap hospitals these days are equipped with 'hi-fis' or a television, and frequently these are turned on quite loud. This blanket of sound is less useful to the blind resident than the more subtle sound cues it covers up.

Echoes can be both a source of information and a cause of interruption for the blind person. They may indicate the presence of a wall nearby; but a continuous rattle of voices and equipment while walking down a long hospital corridor can prevent the direction of particular sounds from being located by a blind person.

Fixed sources of sound in a living area can help a blind person to find his way across the room. These can include a ticking clock, or a (not too loud) radio. By and large, however, many of these details are disregarded in the living units of institutions where visually and mentally handicapped people reside. In larger institutions these residents are usually distributed a few per ward or villa and consequently their particular needs in terms of sound sources and individual verbal

contact with staff are difficult, if not impossible to meet.

Behaviour Problems of the Visually and Mentally Handicapped

The national survey also collected details of various behaviour problems found among blind and partially sighted residents. The most common one among blind residents was various forms of stereotyped behaviour such as rocking to and fro. Various research has indicated that stereotypes are likely to arise from inactivity or boredom. It was interesting to note, therefore that forty-one per cent of blind residents had no form of regular occupation. Of even greater interest, in connection with communication skills, however, was the second most common behaviour problem, self-injury, which was reported in twenty-one per cent of blind residents. Self-injury includes various activities such as head-banging, or eye-poking.

Many attempts have been made to construct an explanation of self-injury in mentally handicapped people including a recent proposal (Cataldo and Harris 1982) that a combined bio-behavioural account should be sought in view of growing evidence for both biochemical and behavioural components in its occurrence. What is of particular relevance to the present topic is the possibility, suggested by some parts of the national survey data, that most self-injurers are also unable to speak. This finding will not be discussed here in detail as further analysis of the data is still required. There is the possibility, however, that interpretation of self-injury as an, albeit inadequate, form of communication could offer a practical means of approaching the problem by improving social contact and access to communication-oriented activities for blind mentally handicapped people.

Conclusions

Communication is of critical importance for visually and mentally handicapped people in way which are not readily apparent. Several concluding comments can be made to draw attention to areas of need which are open to the right sort of practical intervention. Firstly, assessment of optical, ophthalmological and mental development of young children, using some of the newly developed objective methods now becoming available, should be applied as early as possible and praticularly where any developmental delay is suspected. This could help to ensure that appropriate remedial steps are taken to limit the effects of the delay. Secondly, in view of clear evidence that visual handicap is ten times more common in the mentally handicapped population, specialised resources should be developed to serve the living and training needs of these people. Long-stay institutions need to establish less hostile living arrangements and more constructive training opportunities for their visually handicapped residents, while the newly developing community mental handicap services should bear in mind that a

significant proportion of mentally handicapped people will have visual handicaps and will require appropriately specialised opportunities. Thirdly, staff who work with visually and mentally handicapped people should be given the special training which will lead them to 'think' non-visually, and to encourage their clients to develop independence skills such as mobility, language and self-care, which may at first appear to be beyond their limited capabilities. If these sorts of priorities can be met, most of the communication problems faced by visually and mentally handicapped people will be resolved.

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EDUCATING MULTIPLY HANDICAPPED CHILDREN WITH SEVERE BEHAVIOURAL PROBLEMS

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This is an abridged version of the lecture given at the Project Horizon Conference. There are two reasons why this is a short version: first, only part of the lecture was recorded and consequently it could not be transcribed and second, a book** describing the Beech Tree House work has recently been published by Souvenir Press in their Human Horizons Series. This records in greater detail the information presented at the Conference.

The lecture described six years of 'action research' directed towards improving the severe behaviour problems of children, many of whom were multiply handicapped. This work took place in a small residential unit for nine pupils which was staffed so that they received consistent handling and training round the clock. The overall goal for all the children educated between 1977 and 1983 was to give each of them the skills necessary to transfer to a school or unit which would meet their educational and social needs: units which they would have been unable to attend prior to training in Beech Tree House because of their difficult behaviour.

Examples were given of violent, self-injurious and destructive behaviour patterns often displayed by our pupils on entry. These details were offered in order to demonstrate that the unit has succeeded with pupils drawn from that most difficult group of children, those with the severest behaviour problems, who frequently find themselves sedated, restrained and institutionalised. It was emphasised that no drugs were used to control behaviour in Beech Tree House.

A major part of the lecture concerned the way the unit was staffed and the way the staff were trained. It was suggested that if the Beech Tree Project has contributed in any way to improving the methods available to educate mentally handicapped people this contribution has been in the staffing model that has been evolved. The model described was one which attempted to overcome the compartmentalisation that so frequently exists between the various professions caring for and educating mentally handicapped people. Examples of poor practice where children passed between professional groups, say teachers and nurses, with minimal continuity of treatment were all too frequent in the experience of Beech Tree House staff and were regarded by them as impeding the children's progress.

A number of the organisational features which helped to overcome the problems of professional demarcation in Beech Tree House were describe These included the appointment of multirole staff who changed their function as the needs of the children and the timetable dictated - thus teachers became care givers, caregivers taught and the psychologist did night duties; there was a strict adherence to democratic decision making which ranged from the appointment of new staff, through the development of children's programmes to decisions concerning timetabling and conditions of service; and there was regular cross discipline staff training in which everyone participated on an equal basis in lectures, role-playing and micro-teaching.

The central role of parents in Beech Tree House was also stressed. They formed the governing body; a representative helped appoint staff; they attended all case conferences and receive a copy of every report written concerning their child; they could visit at any time; they had the phone numbers of their key residential worker and the head of unit; they were expected to live in the unit and work alongside staff for a weekend at least once each term; they had to accept a member of staff living at home with them for two or three days from time to time to help their child generalise skills learned in the unit to the home environment; and they were on first name terms with every member of staff.

It was stated that Beech Tree House did not offer long term education - a maximum of two years in the unit was the general rule. Because the children's needs were so different no overall curriculum was offered, instead each child was considered in terms of six goal areas. These were the training of Communication Skills; the abandonment of Problem Behaviour; the establishment or enhancement of the ability to Attend to Task; the overcoming of Delayed Continence; the broadening of Self Help Skills; and the training of Transfer Determined Skills which were likely to enhance each young person's chance of succeeding in his or her subsequent school or centre.

It was emphasised that even the most improved pupils were not considered as having been cured by their education in Beech Tree House. It was a central belief of the staff that the difficult behaviour shown by the children on referral was a direct consequence of their learning. In fact, it is suggeste that many disturbing behaviours should be regarded as functional in the environment in which they are learned. For example, head banging may secure attention which is not forthcoming when a child is 'good' and passive. If this functional assumption is correct it follows that such behaviour will recur if the child returns to settings similar to those from which he came. Children whose difficult behaviour appears to be a consequence of emotional trauma have, similarly, been afflicted by environmental factors and are at risk of future breakdown unless they transfer to a supportive environment. It was for these reasons that an active process of working with the staff of units to which Beech Tree House children were transfered was followed.

The lecture concluded with a request to the audience to understand that Beech Tree House used more techniques than Behaviour Modification to restrain children. It was emphasised that while the behavioural approach was appropriate for many of the more severely mentally handicapped children various types of counselling and other therapies were used to help pupils who had relatively sophisticated communication skills.

** Behaviour Problems in Handicapped Children - The Beech Tree House Approach Malcolm C Jones 1983

A COMPUTER AIDED IMPLEMENTATION OF PRECISION TEACHING

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Abstract

The Precision Teaching Method, which is a proven teaching mechanism for the severely mentally handicapped, is extremely staff-intensive in use. This paper describes a computer implementation of the method which is not staff-intensive, and provides a record keeping and archiving facility.

The system has three human interfaces; the handicapped subject, the care staff, and the psychology staff. The handicapped subject is drilled by one of a set of generic games. The subject sees projected pictures, hears (synthesized) utterances, and responds by manipulating toys. All parameters for a given subject are individual, and are changeable by the care staff, who see a console which guides them through the system's use (including such functions as backup). Very little training in its use is needed. The pyschology staff see a statistical printout, from which they may require modifications of the parameters.

The current equipment consists of a voice synthesizer, a high speed random slide projector and a set of special buttons attached to a 64K Z80 with two disk drives, but the system will run on many microcomputers. The system is complete and is about to go into service.

The project has been funded by Project Horizon, a charity associated with Turner Village Hospital, Colchester.

Acknowledgements

The author would like to thank Project Horizon for the funding, but more important, the encouragement and focus for this work. The Department of Computer Science at the University of Essex has provided technician effort and space for the development of the system, and has gifted its word processing software to the project.

Many teachers in Alberta, particularly M Thompson of Lethbridge, have given me access to their classrooms, and suffered the ignorance of a computer scientist. The Turner Village staff, headed by Dr R McKibben, have similarly suffered.

It is they, the psychiatrists, psychologists, educators and particularly the care staff that are providing the heart of this project.

Most of all, I must thank the residents of Turner Village Hospital, Colchester. It is they who will teach us how to design this or any other teaching method.

1 Introduction

Project Horizon is a charity associated with Turner Village Hospital, which is a hospital for the mentally handicapped in Colchester, Essex. The purpose of Project Horizon is to provide specialised facilities to 'raise the horizons' of the residents. These include specialised adventure playgrounds, protected farm environments and the like, which are very well used and considered to be of considerable benefit to the residents. The Specialist Committee of the charity is charged with applying modern technological solutions to some of the problems seen at the hospital. It is from this base that the present work has grown.

The psychology staff can measure with usable accuracy the current and potential capability of a resident under a set of criteria. These criteria include gross and fine motor control, oral and aural capabilities, social skills, symbol manipulation and attention span. These latter two are particularly important for the present work. It is usually the case that a currently low ability in one area severely limits raising ability in another. As an example, a person with a very low attention span is extremely difficult to teach, even though the capacity to learn may be there. If the attention span is increased, then the possibility of increasing performance in other areas is much greater.

In any further program, analysing the results of teaching so as to design further programs is difficult. One of the best teaching mechanisms to aid this is Precision Teaching (Lindl). Basically, Precision Teaching consists of the following stages: the design of putatively suitable teaching programs for a resident; a series of timed short drills using that program; the conversion of the results into numeric quantities; and the design of improved programs from the numbers. The mechanism will be dealt with in Section 2, but note that most of the staff time is spent in paperwork, manipulating results, and the redesign of the teaching programs. The latter would have to take place in any good teaching method, and, indeed, can be much more accurately and easily done with this one. Nevertheless, most of the staff time must be spent away from the resident doing paperwork. This is a major failing of the method.

The Project Horizon system sets out to overcome this failing. It is basically a teaching machine and record keeper. It drills the resident, collects results and timings, does the

maths and presents results. The drills consist of one of a set of 'games', in which the stimuli are projected images and synthesized speech, and the responses are their manipulation of 'toys' mounted on special switches. As the computer is doing the timing and tallying, that load is taken from the staff. Further, the system calculates the statistics, and produces a metric from each drill and set of drills.

It is very important that each resident be treated as an individual; the system must not restrict everyone to the same set of parameters. For example, they may not use the same slides, and even if they do, they may be associated with different concepts, and have different grades of difficulty. In the Project Horizon system ALL parameters can be varied for each individual. This demands good cosmetics, or the staff will not use it; 'it may be flexible, but I don't know how to flex it!'. In fact, a major design criterion was to present clean and friendly interfaces to the three user communities; in this case, the patients, the care staff, and the psychology and educational staff. In particular, they need not know about concepts of the underlying system such as files. It is, in effect, a turnkey system. The design criteria are discussed in Section 3.

Because of fund limitations, it was necessary to restrict the pilot project to individuals with some gross motor control, sight, and hearing. The stimuli are pictures and sounds, and the response is a manipulated toy. The staff can answer for the patient, and then the system is acting as a sophisticated recording device.

Included in the criteria is the need to provide a history of the progress of an individual. The system provides a set of comment facilities, so it can as well be used as a medical notebook. The need for history implies an archive facility, and an easy retrieval mechanism. In an attempt to pervert Murphy's Law, a backup facility is also included, and is semi-automatic.

The hardware costs are quite low. The project funding is $5400. A Vector MZ Z80 based 64K byte micro-computer with two disk drives, a terminal, a printer, a voice synthesizer, and a random access slide projector, together with their controllers, make up the hardware. These are discussed briefly in Section 4. The special controllers are S100 bus devices. They are not complex, so a redesign to another interface would not be difficult.

The software is described in Section 5. It was written in UCSD Pascal (Pascl), and consists of a main program and twelve units, and some auxiliary support programs. It is important that the program structure be good, as modifications to the system over time are inevitable. Further, as funds become available to ease the restrictions on the abilities of the individuals served, new stimulus and response tools will have to be added without disturbing the system as a whole, or consuming much programming time. Some conclusions on this subject are made in Section 6.

At the time of writing, the system was in the process of being delivered. The training of the operating staff, that is, the care staff and the psychologists, has been completed, and took only a short time. Some successful trial runs with children at Turner Village Hospital were made. These were, of course, primarily to help the implementor; even so, the attention span of one child was increased considerably. If the equipment can help the patients to 'raise their horizons', then it will be a success.

2 Precision Teaching

The basic principles of Precision Teaching grow from early research into the behaviour of lower animals in the 1930s. In the 1960s, Lindsley and his students at the University of Kansas began in intensive effort to make the principles applicable to children with mental handicaps, in a form relevant and accessible to teachers (Lind2). He particularly stressed that 'retardation' was not a useful term in the lexicon of teachers of these children (Lind3). Since then, much work has been done, and the method is in use in many centres (Altal, Montl, Batel). There is no doubt that it can be extremely successful (Meffl, Bate2, Perrl).

Precision Teaching is the application of the principles of operant conditioning to educational problems (Pittl, Hirsl). Operant conditioning is concerned with the relationship between behaviour and the environment, and attempts to understand this relationship by gaining knowledge of the factors that modify behaviour. To be useful, some metric must be available, so that results can be compared. Operant conditioning refers to the process in which the frequency of occurrence of a particular behaviour is modified by the consequences of that behaviour.

The Precision Teaching cycle is as follows:

1 Select a behaviour that needs to be strengthened, weakened or modified. In selecting a behaviour, it is important that it be concrete. Terms such as 'attention span' are useful. Terms such as 'intelligence', 'dyslexia', 'emotional disturbance' are not

2 Choose a metric. A typical metric used to judge the efficacy of a program is responsse rate, ie, responses divided by session time

3 Construct a teaching program

4 In a fixed instructional environment, implement the teaching program. During a teaching session, the teacher would have to record tallies of 'correct' and 'incorrect' responses, and the times at

which they occurred

5 Analyze the data, and modify the program if necessary. The analysis of the metric involves graphing it for several sessions, and analyzing the resultant curve

An important feature of the method is the instructional environment. It must be constant over time, or it will interfere with the behaviour.

It can be seen that there is considerable work that must be done without the child present. The design and construction of teaching programs is an example, but this would (or should) be the case with any teaching method. The author has been privileged to watch sessions in schools in Alberta. The timing and tallying is time consuming, and can influence the design of a program. The analysis is time consuming, and takes the teacher away from the child. It is one of the aims of the work described in this paper to reduce this 'non-contact' time to the absolute minimum.

3 System Design Criteria

In setting the design criteria, it was clear that three quite separate 'audiences' were involved: the operating care staff and the psychology staff. Of course the residents must be provided with an interesting environment, and the computer equipment itself must not be part of it. It must be safe. It must provide a good interpretation of the Precision Teaching method. All of the system parameters must be variable for each individual.

The care staff and the psychology staff presented more of a challenge as users. One must assume that they are not familair with computers. The system must be simple to run, and the training period brief. A short training period, and a flexible system are antithetical requirements.

Funding limitations must of course be taken into account. In this Section the design criteria are described, and in Section 6 there is a short discussion as to how well they were met.

Stimuli and Responses

The range of human stimuli is immense. The problem here was one of restriction for a pilot project. Visual stimulus was chosen, as it is fairly cheap. Some of the residents have extremely short attention spans, so changes in stimulus must be rapid. Computer graphics were ruled out as being too abstract. A normal slide projector can provide good images of reality, and creating the images is a simple matter of taking a picture. The

images required are not sophisticated; they must be clear and simple. However, a normal slide projector is much too slow (up to forty seconds) in selecting a random slide. A random access projector, the Kodak RA2000 (Kodal) was chosen, which has an interslide time of about four seconds maximum.

In working with the residents, and in discussion with the psychologists, it became clear that visual stimulus was not enough, and that vocal stimulus was necessary. Again, there is the problem of instant access to an utterance. Tape would provide good quality sound, easy to record; however, selecting a random utterance would either be very slow, or require special, expensive equipment, probably custom designed. Digitized speech would be fast enough, but storage and cost become problems.

An advantage of synthesized speech is data compression, allowing instant access to a random utterance. The problem then becomes the implementation of a voice synthesizer with a reasonable quality. The Votrax SC01A (Votrl) was chosen. It is cheap, and easy to control. A cosmetic for creating utterances then has to be contructed, so the staff can create utterances easily. Given the synthesizer, one might consider text-to-speech techniques (Elovl). Currently, automatic intonation construction is an unsolved problem; as intonation carries much more of the information in an utterance for a resident. This technique is ruled out.

In responding to a stimulus, the resident must provide an input to the system. The input device must be instantly recognisable as an object in the residents normal environment. These objects will vary from resident to resident, as a resident's abilities grow, or the educational aims vary for her. Whatever mechanism is used, it must be absolutely safe, as this is the only part of the system the resident will touch. A pneumatic industrial switch was found that completely isolated the resident (in the electrical sense) from the equipment, and is quite cheap. Toys, pictures or other objects are attached with Velcro. The pressure required to activate the button can be varied within a reasonable range.

Precision Teaching Programs

The Precision Teaching Programs in this system are a set of generic 'games'. Examples:

> Class match games, in which the images must match the toy for a correct response. There will be various types of these with different parameters, and different numbers of classes and difficulties. The method of changing classes and difficulty must be a parameter. A one class game should be allowed, in which the subjects simply changes their environment when they perceive a stimulus.

Yes-no games, in which questions are asked (by an utterance) about the slide images. As well as the parameters for class match games, there will be some to control whether a 'yes' or a 'no' is the correct answer.

Some subjects (self-mutilating children as an example) require special utterances from time to time during a session to help to prevent behaviour which interferes with the training. In all games, the length of the game, the 'no response' timeout, whether a 'special' utterance is required, should be parameters. The definitions of the parameters for each generic game should be kept on auxiliary files with their default values.

In Precision Teaching, data from a single session is less interesting that data across sessions. Session and statistical data should occur in distinct sets.

The creation of new generic games should not require the skills of a computer scientist.

Record Requirements and Accessibility

One can not decide ab initio what information is transient, and what is to be kept. All information must be maintained, and if a change is made, the old information is held. This implies a mechanism for superseding information; that is, making it inaccessible for current use, but leaving it 'on file' for later access if required. Current information should be quickly accessible, and superseded information should be accessible by date. Each item, then, must be date and time stamped.

Information is kept in records. The following record types must be available:

Biographical information, such as name, nickname, age, and birthdate

Raw session data should be kept. Even if a compressed metric of a session with a subject is stored, one may wish to go back to the raw data

Statistical compressions of session data must be stored in such a way that they can be related to the raw data at need

The particular stimulus and response objects must be recorded in detail. Thus records to contain detailed slide, utterance and 'toy' information must be kept. To save space, textual descriptions of slides, utterances and toys, and their default characteristics, should be kept in auxiliary files, separately maintained

The parameters for the game played will vary in detail from game to game, from subject to subject, and over time with a given subject

To a programmer a string of characters is just that. The operators, however, will wish to distinguish among a class of comments. There will be subject-general comments, demographic descriptions, medical data and comments on sessions and progress. These must be separately accessible

Modification of Subject Information

Not all data should be modifiable by the operator. Raw session data and past statistical compressions should remain untouched. The rest of the data should be modifiable, and the cosmetic will vary with record type. The description of some items may change. For example, if a different game is played, different parameter descriptions will be necessary. These descriptions should be kept on auxiliary files, separately maintained. Similarly, descriptions of slides (on a tray by tray basis), toys and utterances should be on auxiliary files, with their default parameters. This information should be displayed during the modification procedure.

The cosmetic for the construction of utterances will be the most difficult. Operators will have to 'take apart' words. For example, the word 'hello' needs the phonemes 'H', 'EH', 'L', 'O', and 'W'. The system should give them as much aid as possible in describing what is to be done to create or modify an utterance. There must be a mechanism for filing and retrieving utterances, so an utterance 'bank' can be available.

System and Data Integrity

Data can be lost through operator error, or through machine malfunction. The system must cope with both, and be designed so as to make operator error as unlikely as possible. Data in questionable files must not be accessible with the normal access mechanisms until it is fixed or declared 'healthy'. If access by the staff to the underlying constructs, such as files and directories, is required, operator error is likely.

The system must be a 'turnkey' device. The operators must not need access to filers, editors, etc. Indeed, they should not be given access to them. They must view the system as a set of 'subjects'.

Nevertheless, problems may occur. Checks must be placed in the data. If a check fails, then the data must be marked unsafe. In particular, if the program fails on an open subject, that subject must be marked unsafe.

In a real system subjects are implemented as files. Large files become unwieldy. An archiving mechanism must be present, and it must be transparent to the operator when requesting historial information. In a real world, data may be lost. A mechanism for backing up a subject must be part of the system.

General Cosmetic Considerations

With any new equipment, training considerations have to be taken into account in the design. The training period should be as short as possible; once the operators know how to turn it on, the ideal would be a 'self-training' program. It should be difficult to make a mistake.

The system must ask its questions of the operators in a uniform way. In particular, it must be clear what is information, and what is a demand for operator response. In general, an operator reply will be either of the 'yes-no' type, or will be a number or string. The former can be input by a single character, while the latter must have a terminator. The system must distinguish between them in its prompts for information. In the case of a 'yes-no' answer, 'no' must always be safe; only a 'yes' answer should cause action. Similarly, a null answer to a number or string evoking question should not cause any action. There should be no 'last chance syndrome'; if a 'no' answer to a question is given in error, the question should come round again.

Of course, NO answer should abort the program; for example, an alphabetic reply when a number is requested should cause a reprompt for the question, or indicate in some way the input was incorrect, and demand a new reply.

Program Structuring and Maintenence

As this is a pilot project, the time available to construct quite a large program is limited. The program will also be undergoing modification as new needs, and errors and limitations of the design are discovered. It is imperative that a debugging harness (inaccessible to the operators) is installed.

More important, all the rules of good structured programming must be applied. Full use of any structuring tools such as units must be made, so that separate testing and compilation is possible as new requirements are discovered. Interaction between units should be kept to minimum.

Statistical Processing

The statistical requirements will vary through time as the operators and the psychology staff learn about the system. The statistical package, must be both part of the system, and

changeable as new requirements are discovered. The ideal would be a generalized package, tailorable by the psychology staff. It is the latter group who primarily will be using this information, and it must be presented to them in an accurate, but palatable way.

4 The Hardware

The Vector MZ with two floppy disk drives was chosen for the system. An Epson MX80F/T Type II printer is also supplied. There are two special interfaces. The projector controller also provides the input port for the response switches, and a rudimentary clock facility. A controller is also required to drive the Votrax chip, and to augment its facilities. In addition, a small 10 watt amplifier and speaker enclosure was constructed.

None of the controllers is complex. They are designed to interface in a simple way to an S100 bus. However, redesign to another standard would not be a difficult task.

Safety was a key criterion. All devices are electrically isolated from the computer, either by opto-isolators, or capacitively in the case of the amplifier-speaker.

The Choice of Computer

The Vector MZ is a Z80 based machine, with an 18-slot S100 bus. It comes complete with two single-sided double-density hard sector Micropolis 5 1/4" disk drives and controller, a memory mapped 80 by 24 character terminal, keyboard and controller, and parallel and RS232 ports. The screen has coarse (160 by 72 pixel) graphics. It is robust in construction, and very reliable.

The CPU board is not ideal; its treatment of S100 interrupts is rudimentary. It is really not the ideal choice for a real-time project. However, it had one overriding advantage: the University of Essex uses the Vector as an initial teaching and secretarial machine. The implementer had no learning curve to climb. In particular, UCSD Pascal was implemented on the configuration.

The Epson printer is a quiet, neat device, capable of graphic output. It is NOT letter quality, but is more than good enough for the statistical output required. In fact, the Department of Computing Science has agreed that the system can be delivered with our own word processing software.

The Projector, Switch and Clock Controller

The RA2000 slide projector has two imputs. The slide is chosen by two BCD digits. If the digits do not match the current position, the projector retracts the current slide, and moves to the new position. The second input is an indication to the projector as to whether it is to drop the slide for projection, or just hold it ready. The projector returns one three-level signal: one level indicates the slide is projected, one that it is retracted, and one that the projector is moving to a new position.

The internal impedences are low, and care must be taken in choosing the drivers. The isolation is done in the control box close to the projector, which also contains facilities for controlling lamp brightness and focus.

The switch interface is a simple parallel port. No debouncing is done in the controller. The isolation is achieved by the switch itself, which is a Radio Spares pneumatic industrial control switch (Radil). The isolation is given by three meter air tubes, which are covered with a tough non-toxic plactic coil to prevent injury to subject or equipment. They are very robust.

The clock is a simple sixteen bit register timing to 1/10 of a second, driven from the 2MHz S100 clock. This provides more than enough precision for the project. A non-volatile calendar board would have been preferable.

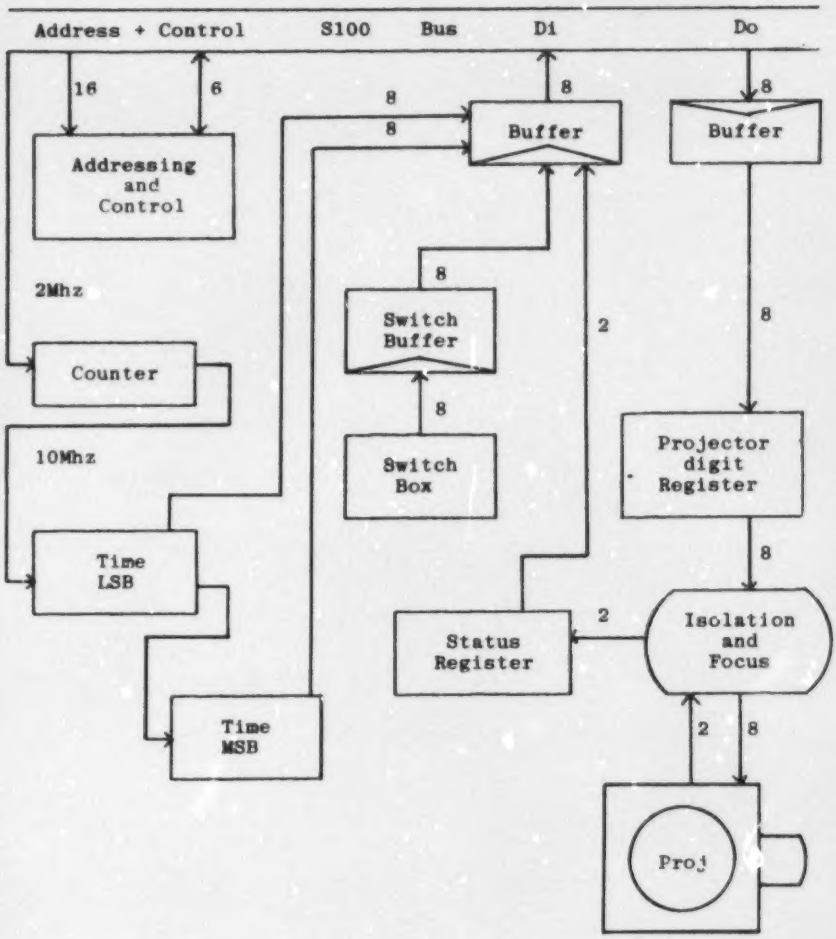
The Voice Synthesizer Controller

The Votrax SC01A synthesizer chip (Votr) is capable of creating sixty four phonemes. In fact, many of them are identical waveforms with different durations. It is clear (Elovl) that intonation contains much of the meaning of an utterance. In fact for some subjects, intonation contains all of the meaning. The chip can produce phonemes in one of four voices. More and finer intonation control is necessary, as the differences in the voice pitches is large.

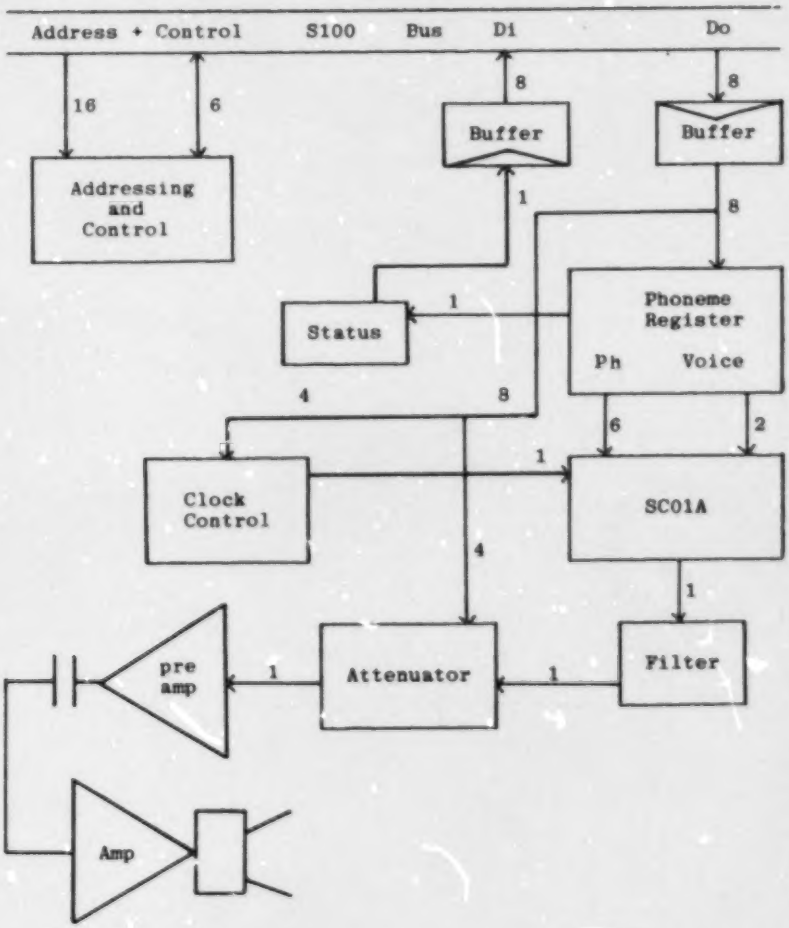
Fine frequency control can be obtained by varying the chip clock around its nominal frequency. This was done with an analogue resistor ladder controlled by a four bit register. The middle ten representations are useful. Volume control was implemented with another resistor ladder on the chip output, also controlled by a four bit register. Both controls are roughly logarithmic.

The controller takes two inputs from the S100 bus. The first contains four volume and four pitch bits. The second contains six phoneme bits and two voice bits and activates the chip. There is one output, namely a completed indication from the chip.

Projector, Switch and Clock Controller Block Diagram



Votrax Controller



The chip output is buffered through a low pass filter and preamp, producing about three volts peak to peak maximum. The output is capacitively coupled to the amplifier.

5 The File System and Software

It was necessary to implement file structures which were flexible, relatively quick to access, and yet not overcomplex. There is one basic record, with variants for the various types required. Records of each type have to be accessed sequentially as if it were in a file of its own. The notions of 'current' and 'superseded' had to be implemented. It was most important that all data be kept, no matter how trivial the change. To support this, an archive system was implemented. A backup facility is also provided. There is auxiliary information kept and maintained separately; an example is slide information.

Like most programs of any size, most of the code is cosmetic in nature: that is, it supplies user friendly interactions for the operators. The heart of the system, running a session with a subject, is one of the smallest parts.

The system maintains one file for each subject, with archive files as the data grows, and backup files as time goes on. A name file contains short descriptions of subjects, and their main file names. Auxiliary files contain slide tray descriptions, toy descriptions, and game descriptions. Special files where single utterances may be stored are also maintained.

The system as supplied contains a main program, which maintains the subject files and name file, runs sessions, provides the parameter change mechanisms and print facilities, and does the statistics. An auxiliary program maintains the game, toy and slide files. The main program can maintain the utterance bank, but an additional program is supplied to do this 'offline'. A recovery program is available to correct files left in an unsafe state by bugs or machine failure.

UCSD Pascal is the implementation language. It has a separate compilation and overlay feature, UNITS, which allow large programs to be built. The rest of this Section briefly describes this facility, and the units constructed for the program. The auxiliary programs are also described.

The Choice of Language

Pascal (Jensl) would not be the first choice of most implementers writing a real-time system. In fact, UCSD Pascal (Pascl) contains multiprocess facilities, including Djykstra's P and V functions (Dijkl). Interrupt routines, however, are difficult to install, and the interprocess communication is unsafe. If a deadly embrace occurs, a reboot of the entire

system is required.

The Unit feature, however, is very useful. Programs can be divided into separate compilation units. Each has an Interface Section, in which the function and variable declarations are made, as they are to be known to other units and programs using them. They have an Implementation Section, in which the functions are defined. A change in the Implementation Section requires a recompilation of that unit only. ADA (Adal) has a similar, if more powerful structure in Packages.

The present system is a pilot project. UCSD Pascal was primarily chosen because it did not require the implementor to install a language, and climb the learning curve of THAT language on THAT system.

The Turnkey Environment and the Chainer Unit

If the operator is given normal access to system facilities such as editors and filers, finger trouble is inevitable. The system must appear as a turnkey system. They must know, of course, how to load disks, and bootstrap. The first program run after the bootstrap is automatically SYSTEM.STARTUP. The startup program provided asks the current date, and then invokes the Chainer unit.

This unit is invoked at the termination of all the system programs. It displays a menu of descriptions of all of the programs available to the operator, and asks her to select one. The unit then chains to the requested program. In this way, the Pascal system itself is never seen by the operator. The currently available programs are:

the main program

the auxiliary file handler

an auxiliary voice synthesizer program

a file recovery program

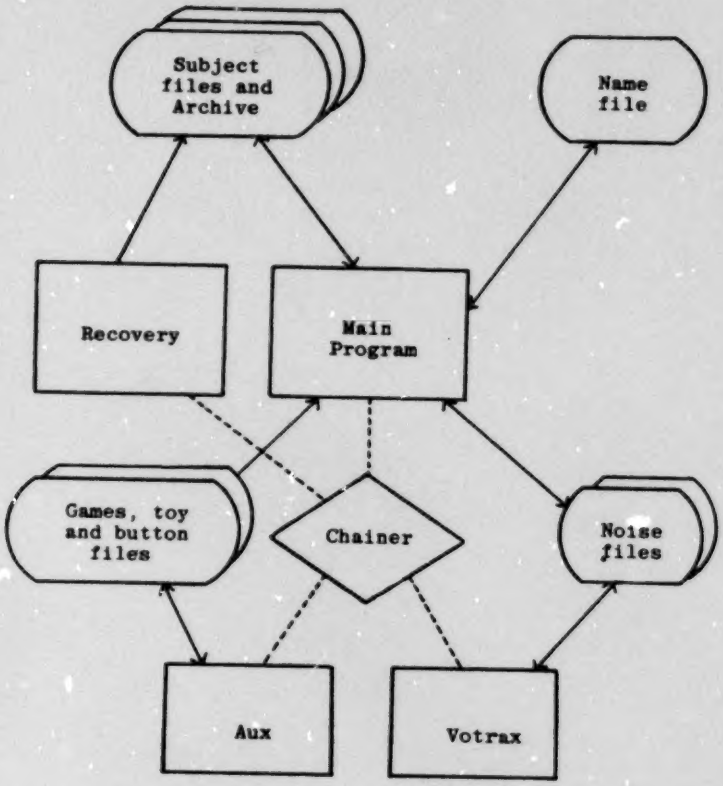
a 'toy' speech to text program

Of course, some mechanism must be available so that the maintainer can get into the system. Currently that choice is displayed on the menu as well, with a warning. As the chainer unit branches to all operator programs, we use this opportunity to show the relationships of the programs to the files, and to the chainer unit.

The Main Program, and Subject Selection

The first function of the main program is to ask the

Relationships of Programs to Files



operator to turn on the speaker and projector. It then displays a menu of currently known subjects. This information is held in the file NAMES.TEXT, which consists of pairs of lines; the first is a description of the subject, and the second is a disk and filename. The operator chooses a subject.

If the subject file is present on the mounted disks, the biographical information is displayed, and the program carries on to its next Section. If not, the reason is displayed. The operator is given a chance to try again, or to name a file. If she chooses the latter, and no file exists, then she is asked if a new one is to be made, of what size, and whether the name and a description is to be added to NAMES.TEXT. There is no delete facility on the names file.

The program checks the date of the last backup operation. If it is past a week, the operator is asked whether the backup procedure is to be initiated. If there is little space left on the file, the operator is asked to initiate an archive procedure.

Once a subject file has been opened, the operator is asked cyclically which of the program facilities are required. These are:

information modification

information display and printing

running a system

statistical output

choosing a new subject

leaving the system through the chainer unit

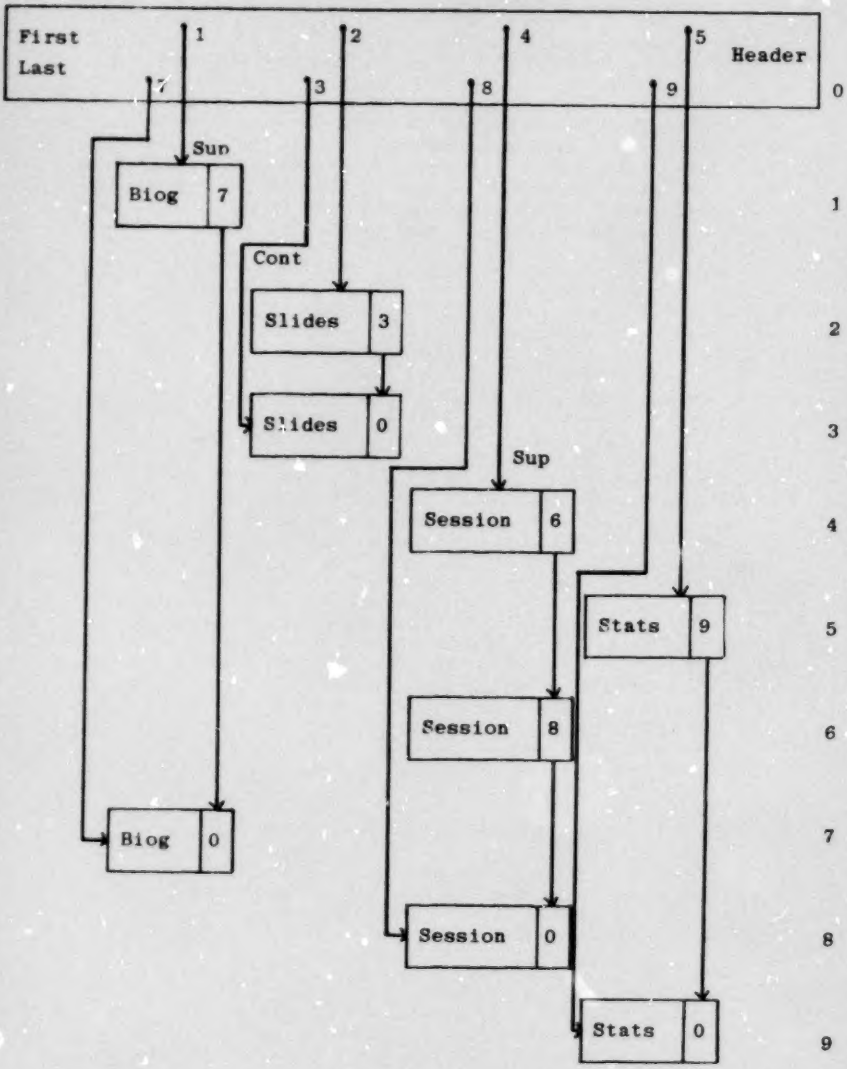
Subject File Definition and Manipulation

The subject file structure, and the routines for manipulating it are the province of the SUBFILEDEF unit. Its interface defines the record variants.

Each record has a common section containing a time and date stamp, the record address of the next record of this type, a superseded flag and a continuation flag. For some record types, it may be necessary for a logical record to be held in more than one physical record; comments are a good example of where this may be necessary. The rest of the record is a variant depending upon a record type flag.

Biographical records contain name, familiar name, date of birth, sex, and some psychological data about the subject. Comment records are basically character strings, but as the staff distinguish between comments (for instance, between comments

Example of Subfile Record Structure



about a session, and demographic comments), a subtype is stored.

Slides and toys have their own record types, in which the characteristics of the slide for this subject are stored. Both these types reference an auxiliary file, in which textual descriptions, and default values for the characteristics are kept.

There is a set of generic games, one of which a subject may be playing. The subject parameters will vary, and are kept in a suitable record. This record references an auxiliary description file. The utterances will also be tailored to the subject, and have a record type. These records each contain a phoneme string, and a textual description. However, the purpose of the utterance is held in the auxiliary file of the current game. An utterance whose purpose is affirmation may be 'good' for one subject, and 'terrific' for another.

The session record records the time of every event in a session: which slide, its class, and the response. For 'yes-no' games, the question sense is also recorded. This is the raw data for the statistical package, which creates statistical records for each session set.

The zero'th record of each file is a header. It contains backup and archive information, record counts, and a note of the earliest dated record of each type in the file to facilitate archive retrieval. It also contains the record numbers of the first and last record of each type in the file. As all records of a type are linked, all the records of one type appear as a sequential set, and can be so accessed.

The SUBFILEDEF unit contains the procedures that manipulate the file structure described above. The open routine does a special check for validity, and marks the file open. The close routine marks it closed. This ensures that, if the program crashes while a subject file is open, it becomes inaccessible to the program. The access routines include procedures to get the next record, check for end of 'file' for that type, 'rewind' to the first of a type, and write and rewrite record routines.

Subject Record Modification, Display and Printing

There are three entries into the SUBMP unit; record display and printing, record modification, and comment record creation. All three are used by the main program, but the latter is used where ever comments need to created.

The print and display entry asks the user to select an output medium, which can be printer, the console, or a named file. She can select to print current records only, records since some date (which may involve an automatic backtrack through the archives) or the whole subject file. IF the whole file is not to be printed (which is the usual case; this facility is used

for debugging only) then a menu of all record types is displayed, and a selection made. If comment records are selected, a subsidiary menu allows selection of one comment type, or all of them.

The record modification entry asks the user what current record type is to be changed (or created, for a new subject). The header, session, comment and statistical records may not be modified. Each modifiable type has a cosmetic to suit its data. Those that relate to auxiliary files have the auxiliary description data displayed. The records are NOT overwritten. The old record is superseded, and a new record supplied.

The comment creation entry is a simple device which allows a long comment to be created. The comment can extend over record boundaries, but the operator is not aware of this. It has rudimentary editing facilities.

Sessions

This unit contains the heart of the system. Its single entry sets up and runs a session. The unit will:

Extract from the current game, slide, toy and utterance records all information needed to run a session. The slides may be checked by the operator during this phase

Check the equipment, and ask the operator to check that the toys are correct. Ask her to get the subject ready

Set the chronograph and run the session, creating a new session record

Call the statistical package, which will update the current statistical record, or create a new one

The second phase controls the sequence of utterances and slide changes, and notes the responses. All events are timed to the nearest tenth of a second. The sequence will change from game to game. A typical game is MATCH1. In this game, the subject is required to match stimuli to responses. The following table will describe some of the game parameters, and give the values used for a given subject.

Parameter	Unit	Range	Default	Subject Value
Game length	tenths	0 .. 32000	600	600
No response delay	tenths	0 .. 32000	100	100
Class count		1 .. 8		2
Class names				Yellow Blue
Class change if correct	x / 10	0 .. 10	5	5
Class change if wrong	x / 10	0 .. 10	0	0
Extra noise	Response count		0	5

This game requires a set of utterances, which again will vary from subject to subject. For this game, seven are required, as shown below. The subject values are shown as textual representations, and therefore cannot describe the intonation and voicing used for a subject.

Utterance Class	Subject Value
Affirmative	Terrific
Negative	No, Dave, that was . . .
Extra	Don't DO that!
Class 1	Yellow
Class 2	Blue

In this game, the session unit cycles through the following sequence until the game parameter time is reached, or the operator terminates the game.

1 Calculate new difficulty and class depending upon the old values, the game parameters, and the current right/wrong counts

2 Pick a slide which matches these criteria as closely as possible

3 Issue the relevant describing utterance, and show the slide, noting the time

4 Wait for a response. If the waiting period exceeds the response wait time in the game parameters,

assume it is wrong. Note the time

5 If the answer if correct, issue the affirmative utterance. If it is wrong, issue the concatenation of the negative utterance and the correct describing utterance ('No, Dave, that was', 'Blue')

6 If the extra utterance is required, and the relevant game parameter is reached, issue the utterance, and zero the count

7 Store the event in the session record. The slide, response, times, correct and answered class are stored. 'No response' is distinguished from 'wrong'

The session unit then invokes the statistics package, and exits.

The Synthesizer Unit

This unit is an extreme example of the ratio of cosmetic to algorithmic code. The code to drive the synthesizer is two lines of Pascal, while the code to drive an utterance is ten lines long. The rest of the three files of text is cosmetic.

The synthesizer and its controller are capable of sixty three phonemes, in four voices at fifteen different pitch levels, and fifteen volume levels. The utterance record consists of an array of these, enough for about ten seconds of speech, a text line, and a number to key the utterance to the game in use. The driving code is very simple.

The cosmetic code is complex. It includes a help facility, a picture with examples of the available phonemes, 'thermometers' for the current pitch, volume, and voice levels, and a display of the current utterance. There are commands to add, delete, change, and create phonemes within an utterance, and commands to sing an utterance, or a single phoneme. The unit can file utterances away on disk and retrieve them.

Only a few utterances can appear on the screen at a time, so facilities for windowing are available.

The Statistics Package

The statistical unit has three entries, one of which is called each session. This entry compresses the raw session data. The second entry is called from the main loop, and does cross-session processing. The third prints a statistical record.

The package maintains one record (or a set of continued records) per session set. It is implemented as a variant structure, so that different compressions can be kept. The print

entry is placed in this unit so that as new statistical requirements come to light, only this unit need be changed. Currently, only one compression is available: a simple count of correctly, incorrectly and unanswered stimuli, and the average response time. New compressions are easy to add.

The cross-session entry is rudimentary. It simply prints a statistical record in a different form.

The Carousel and Timing Unit

This unit combines the projector driving, response detecting and timing functions. The key carousel facility is displaying a slide. One can choose to move and display, or just move. In the latter case, the program can drop the slide quickly, as it has already been moved to the correct place.

The responses are currently simple switches, and the controller is simply a buffer. For some input devices, such as joysticks, the 'jitter' information when the subject has poor fine motor control, can be used to interpret the subject's intent. For this reason, no debouncing is done in the controller. In the present case, debouncing is all the signal processing that is required, and it is done in software in this unit.

The timing facilities model a wrist chronometer; there is a timing register, and a clock register. The timing register can be stopped, started, and the current 'lap' time noted. The clock register, once set up, simply records the passing of real time. Both work to the nearest tenth of a second.

The Library and Date Units

It is imperative that the program performs its own error recovery. As an example, an incorrect keyboard input, such as an alphabetic when a numeric is called for, should never cause a system error. For this reason, a library unit was constructed with several handy functions. They include:

a bullet-proof number reader

a limit checking number reader

a length checking string reader

a 'prompt' routine

a 'yes-no' function

The industry has seen hundreds of variations on the syntax of a date, and we have implemented another. The date unit provides this function, as well as functions to read and set the

system date, functions to extract the day of the week from a date, and 'day number' functions so that the number of days between two dates can be calculated.

6 Conclusions and Suggestions for Further Work

The equipment has been delivered to Turner Village Hospital. The training of operators is complete, and took little time. Trial runs with residents at the hospital have been successful. Full clinical studies are in the process of being designed by the psychology staff. It is the results of these studies that will prove whether this work is truly successful, but the description of them is beyond the competence of this author. It is safest to say at this point, that the psychologists and care staff are happy with the system, and with its capabilities. The rest of this section will indicate how well the system met its design criteria, and suggest further work.

The stimuli, (that is the projected pictures and utterances) appear to be adequate for the teaching task required of them. The projector changes slides just fast enough in the worst case to keep the interest of the subject. The slides, of course, are limited to static images.

The voice synthesizer is surprisingly successful. One operator characterized the synthesizer output as 'a cross between Henry Kissinger and a Dalek'. Nevertheless, those subjects with some understanding of human speech have little trouble understanding and reacting to the sounds. Those who react to intonation only take a little longer to train.

It is clear that video output would be an improvement. A random access video disk would allow the recording of vignettes as well as stills. Recording would take little more skill than photography does now, or perhaps less, as there would be instant feedback. The utterances would be recorded speech using the same recording medium. This solution is well beyond the current budget.

The response devices have been reliable. Large 'toys' do cause some problems, as they can roll off the buttons. Fixing the buttons on boards would correct this, but make them less flexible to use. The current mechanism is only adequate for subjects with reasonable gross motor control.

The generic games installed appear more that adequate for the pilot study. Most new games suggested by the psychologists have been trivial to install. However, the implemented data structures do not cope with complex games. An example is a relationship game (eg under-over, bigger-smaller) in which each slide carries more than one relationship (a big ball over a small table). For this game, an utterance of the form "'Is the', 'ball', 'over', 'the table'" would have to be constructed. There

is scope here for the application of the techniques of expert systems.

All the information specified in the design criteria is kept, with the individual-to-individual flexibility specified. It provides the constant environment required. The system copes well with the problems of archiving and data integrity. Once the system is bootstrapped, it appears as a turnkey system. If mistakes are made, they do not destroy data. They may leave superseded information in the archive which has no value.

The statistical output is the weakest part of the system. A decision was made not to implement elaborate graphical output until the study had run for some time, and the psychologists were clear about the statistics needed. As the raw data is never lost, this is not a problem. The relatively primitive current implementation is easy to augment. It appears to be adequate for the pilot study. This is a very fruitful area for further work.

The test of the cosmetics has been the operator training time. It has averaged three hours. The one area where a change in 'style' may be required is in creating utterances. Perhaps a better solution would be to install an utterance in a 'Dalek'-like way, and then use a finger on a touch sensitive screen to vary the pitch and volume. This would be fruitful area of work for someone interested in Man-Machine Interfaces.

The programs have been well integrated into the turnkey system with the chainer unit. The structure seemed adequate during development; there is very little cross-coupling between units. As an example, an experiment was made with the installation of a blow tube instead of the switches. The carousel unit changes were not difficult, and no other changes were needed.

The system appears to be a success in its own terms. Subjects enjoy it, and even though at the time of writing, the full pilot study is not in progress, are gaining from it. It is easy to use, and reliable. Nevertheless, the test of its usefulness will be on the wards and in ordinary living. If improvements here can be attributed to the use of this system, then it will be truly a useful teaching tool.

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OVERCOMING PROBLEMS FACING PARENTS AND RELATIVES

TONY GREAVES (Director of Nursing Services, Mental Handicap Unit, NE Essex)

I would like to give a very personal view of the way I see the major problems which face parents and relatives:

- what they are

- why they have persisted so long

- how they can be improved.

The major problem, so well described by many workers in the field, is the subject of this conference - COMMUNICATION - or failures in it with relatives.

I think it is because there has been historically such a lack of resources in the field of mental handicap that it has been almost an embarrassment to involve relatives too closely. This has resulted in relatives often feeling excluded from the activities of the institution.

Working with groups of people like the National Development Team in different parts of the country has for me been a revelation into major problems facing parents and relatives. When one listens to parents at meetings, the same problems seem to exist. These can be listed under three headings as a failure to:

1 NOTIFY - changes, movements, transfers

2 EXPLAIN - treatment, personal circumstances, money

3 INVOLVE - assessment, planning, recreation

It would be unfair to say that this is the same everywhere - some hospitals have good insight into the problems facing relatives and are very sensitive to their needs, involving them in many aspects of hospital life. But to a lesser or greater degree, communication is the greatest problem we face.

When meeting groups of parents and relatives it seems so easy to advise officers of the many simple ways of overcoming these difficulties and yet not acknowledge that the same problem exists for you. I suspect that the problems I have mentioned exist in fields other than mental handicap care and with

different authorities.

Why then should there be problems in communicating effectively with parents? One reason must be because provision generally for the mentally handicapped was so poor that the environment for full contact was generally poor for the resident as well as the relative. Shift changes and staff movement mean that continuity of contact is hard to achieve. Hierarchies seem so complex that there is little wonder that relatives fail to get the hang of it. Even the senior officers always seem to be changing, and for people to keep up with 'who is who' means that communications are attenuated to say the least.

What is this problem of institutional care that makes liaison with the non-professionals so difficult? There is, after all, little disagreement on the six major points that mentally handicapped people in hospital care should have:

1 Privacy: territory

2 Small group living

3 Personal choice

4 Freedom to socialise

5 Absence of regimentation

6 A chance to increase personal competence

Institutional Care

The historical distribution of hospital provision has certainly led to many of our present difficulties. Hospitals many miles away from the people they serve make it difficult for relatives to keep in touch with the residents and staff who care for them, never mind get involved in the activities of the hospital. There are examples of large hospitals, one of which is in the other's catchment area, each struggling for its individual share in resources, financial and manpower.

Obsolete buildings and decaying fabric only serve to isolate them further and lower morale. Many hospitals as we know, are still overcrowded and have to shelter people who have no real need for National Health Service care.

These factors certainly produced an environment which was extremely difficult to staff, and to bring to bear on the problems of care and training people of different professions, speech, physio- and occupational therapy. The environment for expert care and therapy to be given is critical, and many hospitals just could not provide it - and still cannot.

Combined with an absence of community support, and

indifference towards voluntary involvement, and rigid management attitudes, it was not surprising that changes were becoming imperative. To quote James Elliott, who said that the cry from the hospitals was 'too many patients: too few staff: too little money', to which one might add 'too few ideas'. This statement may be true in many instances, but it would be unwise to underestimate 'too little money' because it leads me into the next part of my paper, which I head 'Improving the Image'.

Improving the Image

It should be said that hospitals of the mentally handicapped have improved in most aspects of care. They are generally smaller, have fewer residents; the most able have been rehabilitated. Some Districts have resolved the many catchment area problems. Staffing levels have improved considerably over the last few years.

Sums of money have been spent on ward upgrading schemes, and large wards can be seen subdivided. Furniture is more domestic, and many areas are carpeted. The old problems associated with the fabric of building still remain; patching up seems the most that can be hoped for.

It is now possible to place most residents in activity areas, although the structural environment is not always the most suitable. There is more help from para-medical specialities.

With the appointment of Voluntary Organisers have come a stream of well motivated people, especially youngsters, who are involved with the lives of the residents. Parent and relatives organisations do a lot with the League of Friends to raise funds for equipment, and take a very real interest. Improved monitoring, derived from participation from groups of non-professionals, is a method of evaluation of services which should not be overlooked.

Rehabilitation

During the period following Better Services for the Mentally Handicapped, and in recognition of the fact that hospitals had many people who did not need medical and nursing care, a programme of rehabilitation resulted in the discharge of large numbers of people into the community. I believe that this in itself started to give rise to some anxieties in the hearts of relatives; although many from the hospitals settled happily, there were others who missed the security of the hospital with its structured life. Relatives to a certain extent started to doubt the wisdom of some examples of community care. There was no denying that resources were limited enough providing full care for the more handicapped in the hospitals, so that when the need became apparent for giving continuing support in the community additional resources were just not available.

Often the problem for the rehabilitated was that they were prepared and placed in the open community rather than the sheltered community.

The many reports and inquiries between 1965 and 1975 only served to remind authorities that for a long time to come hospitals would have to concentrate on what was crudely called 'tarting up' - a cosmetic exercise for buildings and a new image for hospitals. The Gunzburgs have warned us of the 'tarted up old wards - worse still, the brand new ones which can be seen in some areas of the country which produce all the old faults, but this time in glorious technicolour'.

It very soon becomes apparent to anyone experienced in institutional care that in the quest for reduction in numbers of residents and the domestication of the hospital environment the need for vast sums of money is never ending. What is the return on the investment if, indeed, a substantial investment of capital is made? Not a lot! Firstly there is a limit to the reduction of residents on a ward just the same as there is a limit to the size of house one can live in comfortably. Secondly, unless the ward can be fully redesigned and transformed into flatlets, then we are back to that Gunzburg rightly claimed to be a 'tarting up' process.

Another feature in reducing numbers is that very quickly it is realised that ground floor accommodation is really what is needed most, and when that has been achieved it should be to enable small group living on as near a domestic scale as possible. It is at this time, when large hospitals reach this point in development, that the real message of Better Services, Peggy Jay and many National Development Group and Team reports, combined with the feelings of many parents and relatives that a rethink of mental handicap policy is imperative.

All things being equal, in improving the image of the hospital the institution will now present itself to the public and the relatives as a smaller, more efficient hospital, hopefully serving its appropriate catchment area. It will have upgraded wards, and be able to offer care and training in a more domestic environment. The ratio of staff to residents no doubt will have improved out of all recognition. Following national and local policy, children in care will be far fewer, and probably will be accommodated in houses away from the hospital, enjoying a life style as near normal as it is possible to achieve.

Is this, then, the ultimate model of care that is practicable to achieve? For many parents and staff I think that it may well be a most satisfactory state of development, and it is likely that communcation with all those groups would have by this time improved considerably.

I read a letter recently from a parent concerned about changes in policy which she had read about, and she finished by

saying that she fully understood that changes in the care of mentally handicapped people historically take a long time to come about. A friend of mine described this as the 'inevitability of gradualness', which I believe to be true - although one feels that the speed of change is increasing.

With the evolution of the pattern of care over the past decade or so, how does this meet the needs of parents and relatives who are enlightened and have high expectations of the service?

Problems Facing Parents

To me there appear to be two broad groups of parents and relatives attempting to communicate their needs to the providers of services. First there is a large group of relatives who have someone in hospital care, and that person may well have made considerable progress in that environment. Parents in this group may wish for nothing better than for proposed plans for improvement to continue - to retain the good links with care and therapy staff they have known for many years. For this group the total care, training and recreation of their relative is what they need most of all.

There is another group, however, with a somewhat different viewpoint and needs. They may have always looked after their handicapped relative themselves, using community facilities and services other than the Health Service. Because of increasing handicaps and perhaps their age, or maybe problems of behaviour, they can no longer cope. These people are saying that what they want for their relative is skilled assessment, short term or respite care and the support of a team of experts and, when they can no longer manage, full term care as near to where they live as possible. They would prefer provision to be small - on a domestic scale, to be a resource centre for skills as well as for equipment, to be a place where they will find little difficulty in easy communication and involvement in the activities of the home.

It is primarily to meet the needs of these groups of people that this Health Authority is developing what we call Neighbourhood Support Services. The plans we have fit into the regional strategy for care of the mentally handicapped. Before I go on to discuss proposed new services there is an important factor to mention. There is an obligation to care for all those people who cannot in the short or medium term be accommodated anywhere else but in hospital, even though they may have originally lived a long way away. Parents are naturally often concerned about friendships that may have been formed in the hospitals, and are seeking an assurance that these relationships will be considered before movements, especially out of District, are made.

Neighbourhood Support Services - Which Pattern to Choose?

In a discussion of communication problems with parents and relatives, the whole area of community provision for the mentally handicapped must rank high on the list of anxieties, and is where communication can become distorted. Parents often receive confused signals about community care which lead to feelings of insecurity and uncertainty. They hear and read about hospital closures, changes in catchment areas and shortage of resources. To say that homes will be set up in the community must lead many to think of a proliferation of unstaffed group homes, or at best a minimal staffing situation.

The establishment of future services has masqueraded under many descriptions and this has contributed further to the confusion. They have names like:

Base Hospital and Satellite Units

Nucleus Hospital and Community Units

Core and Cluster Developments

When you think of it, leaving semantics aside, they are all variations on a theme - a rose by another name. Many authorities have wrestled with the problem of the name, but perhaps 'Core and Cluster' has been the best publicised. But to describe the scale of the service and its local nature in Colchester we have chosen the term 'Neighbourhood Support Services'.

Well then, what are they? For a long time to come there will be a need for a base hospital caring for the more heavily handicapped and perhaps the more disturbed of our residents, and a major centre for specialist skills. The present need for investment of large sums of capital in modernising and refurnishing of existing wards and departments and, most importantly, creating ground floor living space will remain. The hospital will continue to be the base for staff training and for many facilities like Hydrotherapy and Project Horizon which in the short term it will be impossible to duplicate.

That, then is the major Health Service provision in the District; with its name of Turner Village it should present a smaller, more effective and less institutional image.

Because this District has a number of large old houses already in the community - many giving a fairly domestic style of living - there is a temptation to upgrade some of them and then expect them to provide a community service. We have examined this proposition and firmly reject it for several reasons:

1 Cost - there would be no saving in the capital cost

2 The major need is for ground floor accommodation

3 Fabric maintenance of an old building - many are one hundred years old

4 Small group living - difficult to achieve by adaptation

To set the scene for describing Neighbourhood Support homes one has to realise that in an essentially rural Health District such as this one there are a number of small towns who should have services a lot nearer to them if real community involvement and good communication with relatives is to prevail. I would like at this point to quote from Care in the Community, which says quite clearly:

> 'Most people who need long term care can and should be looked after in the community. This is what most of them want for themselves, and what those responsible for their care believe to be the best.'

If we accept this statement, and I believe many parents and relatives do, then the pattern of care is clear. What is needed is a local service. Having rejected modification of the existing houses, which would have some advantages, especially acceptability, the most effective solution is to build new.

To satisfy those six major needs that mentally handicapped people in care have, the design is fairly straightforward. It should be of bungalow design with pitched roof - ground floor - in separate family groups of say six people, with independent facilities including kitchen grouped around central services. A unit such as this should be designed to facilitate care for the most handicapped if it is to provide a really neighbourhood service. There may well be a range of ability groups. Most importantly, parents and relatives must see these units as resource centres and places where they can become closely involved in every aspect of the lives of the residents.

One of the major doubts that parents and relatives would have in comparing a twenty-four place Health Service community home with the hospital is the availability of a full programme of activities, both training and recreational. As part of the design of each of the neighbourhood support homes a multi-purpose activity centre capable of being used seven days a week is very much a part of the project. Another worry they may have would be the availability of therapists - speech, physio - and occupational - but it is recognised that the skilled input of these people is vital to the effective running of these homes.

Community Mental Handicap Teams

The role of this multidisciplinary team has been well publicised, but at a conference discussing all aspects of communication in mental handicap the team's importance should be

mentioned. In the design of neighbourhood support unit it is envisaged that one of its important functions will be as a base for the team. The key full time workers, the community nurse and the social worker, actively involved with parents and relatives play an important part is establishing effective communication. Community psychologists and remedial therapists may well work between two or more units, but the consultant psychiatrist and his team will have a wider brief.

Matching the Community Services

Although I have spent a considerable time in discussing the part that Health has to play in the development of future services, there is no doubt that the aim should be joint planning with the personnel of Social Services, education and private and voluntary organisations. Facilities thus designed should complement each other and information and expertise sharing should be as a matter of course. Such a spirit of working together would give parents considerable assurance and, to a certain extent, choices of provision for their children.

Who is to Care?

To me it appears that in compiling the paper 'Care in the Community' great pains have been taken to consult with everyone devoted to the care of mentally handicapped people. The follow-up document states quite clearly that while the responsibility for the mental handicap services should remain as it is there should be even closer co-operation and planning.

I believe that the professionally trained nurse of the mentally handicapped will continue to bring to bear expertise in the care, social skills training and recreation of those people needing such services. The new nurse training syllabus will provide wider experience to equip nurses to give care in other than the hospital setting. The Nursing Process is an integral part of that training and ensures that care programmes are designed for each person. Working as they will in the future in community settings as well as in the hospitals, nurses will have to move more easily amongst other professionals, relatives and other care staff and volunteers.

The far-reaching post-basic training now avaliable to qualified nurses, from various sources means that they can receive on-going training in aspects of care such as behaviour modification, community care, non-verbal communication systems and other areas.

It is in joint training that many opportunities exist to bridge communication with other disciplines and care staff. Certainly, combining in-service training of Nursing Assistants and Care Assistants has proved already to have possibilities for the future. There seems no reason why training facilities should

not be offered to care staff of voluntary and private organisations.

Conclusions

We have perhaps covered a lot of ground in this very important discussion of problems facing parents and relatives. No doubt the way forward as seen by this District and Regional Health Authority will have its critics, but I think if we consider again the six major needs of mentally handicapped people:

1 Privacy: territory

2 Small group living

3 Personal choice

4 Freedom to socialise

5 Absence of regimentation

6 A chance to increase personal competence

it would seem to me that a large hospital, by definition, would find it very difficult indeed to satisfy all these needs: whereas there is a very real possibility in a small hospital and a number of neighbourhood support homes, of creating the model most likely to provide service sensitive to the needs of mentally handicapped people, their parents and families.

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IS THAT ALL RIGHT FOR YOU?

WILLIAM APPS (Parent)

If you look down the conference programme you will see that all the speakers so far have been identified by the particular job which they do and this helps to establish in your mind the right they have to speak to you in the first place. It gives them some authority. But there are two of us, Maurice Collins and I, who are just labelled 'parents' and so it may be helpful to provide you with some information about my situation so that you have a base on which to set what I say.

But before I do that I think a word of explanation is due about the title I have given this talk. 'Is that all right for you?'

It is derived from that of the radio programme 'Does he take sugar?' This is a quite brilliant title in that it implies so much. It tells us, in a few words, a great deal about the handicapped people for whom the programme is intended and a very great deal about people's attitudes to them. It suggests that the handicapped person needs an 'interpreter' or an 'agent' and that any process of communication is, at least, a three-sided activity and not direct between two people. Once this becomes the case, of course, some of the choices which should be freely available to the handicapped person may be lost - they are made over to the 'agent' or 'interpreter' and, as soon as this occurs, the quality of life enjoyed by the handicapped person becomes dependent upon the sensitivity, the awareness, and the degree of self-effacement which the 'agent' concerned brings to bear upon the situation.

I have said that my title is a derivation; the change is meant to suggest several things. The most important, of course, is that there should be, and there can be, direct communication between the person preparing the tea and so asking about the sugar, and the handicapped person drinking it. This, in turn, expresses a fundamental change of attitude on the part of the tea lady. And I shall be returning later to the need for changes of attitude.

But the other element which the change in the question is meant to imply is that everyone involved in helping the handicapped person should be asked the new question of my title and should certainly be asking it of each other.

- The doctor should ask the parents, 'Is that all right for you?'

- The parents should ask the teacher, 'Is that all right for you?'
- The teacher should ask the doctor, 'Is that all right for you?'

Ideally, of course, when they ask each other this question they should all be in the same room, talking together. But that, again, is an issue to which I shall be returning later.

Now, to get back to some information about my situation:-

First of all you must realise that I am only one half of the team - my wife is sitting with you, listening to me, but she could just as well be here and I there. What has happened has happened to US and the response to it is a joint one.

We have a daughter, Christine, who is now twenty eight and is in Villa Eleven of Turner Village. We live in Colchester so that we are near her and so that she can be with us as part of the family for at least two days each week. She is a right-sided hemiplegic, cannot speak, and is doubly incontinent.

Christine has lived in hospital since she was fourteen, having previously spent two years away from us at a Rudolf Steiner residential school in the Midlands. Between leaving the Steiner school and entering hospital she lived at home with us in London and attended what was then known as a Junior Training Centre. She first entered hospital in 1969 and transferred to Turner Village when we moved to Essex in 1972.

The importance of these facts is that they establish the time scale of our experience. They indicate that Christine was born at a time when attitudes, generally, were somewhat different from now. Somewhat different but not totally different. It is one of the sadnesses of my experience with the National Development Team that less has changed than one had thought and, certainly, less than one had hoped.

Of course one of the main changes came through the 1970 Education Act. Christine came before this event and so, by a series of rather ludicrous tests, was diagnosed as 'ineducable' and thus became the responsibility of the Health Authority. She eventually received some 'care' at the Junior Training Centre but only received 'education' as such when we paid for her to go to private teachers and to the Steiner school.

Anyone involved in this work is now beginning to experience some of the after-effects of the mandatory education of the handicapped. Parents have been better able to cope at home by having their children at school during the day. It is interesting to realise that the follow-up to the work in Sheffield by the DHSS, in setting up a range of facilities for

the mentally handicapped, showed that some of the statistics on which the provision was based were wildly out. This was most extreme in the case of long-term residential care for mentally handicapped children. Far fewer places were needed than was originally thought. In most instances this was due to the fact that children were out at school during the day and so life could be nearer to normal for other members of the family. In other cases considerable home-support services were provided from the first-class assessment and treatment unit. The need proved to be not for long-stay care but for short-stay at weekends and for holiday periods.

The other after-effect of the Act is the raising of the expectations of parents, of teachers, and of the handicapped themselves. Many children who entered the Education system when the Act first came into force are now reaching the age of leaving school. The recent sixteen-nineteen issue will extend their stay for a while but the big question will then be 'What happens now?'

The children and young adults have been stimulated and are reaching greater potential than ever before. How can this momentum be maintained after they leave the Education system? How can the teachers be encouraged to believe that all their work has been of some avail and will not quickly be undone? And how are families to cope when John or Jane is back at home for twenty four hours each day? Adult Training Centres and Special Care Units are not yet geared to this new situation.

I suspect that a higher percentage of parents of handicapped children are now better educated, more literate, more aware of their rights and so have higher expectations than in any previous generation. There will still be some who prefer to put John or Jane away and forget about them but they will be a minority and far fewer than in the past. Most will want to be involved and to have a proper say in what happens to their children.

The Education Act changes resulted from the pressure brought to bear by parents' organisations such as the National Society for Mentally Handicapped Children. There are, and I suspect there will continue to be, new points at which pressure needs to be applied. MENCAP, which succeeded the National Society, may still have an important part to play in this.

As far as the general public is concerned much still needs to be done. Although the last twenty years or so have heralded a marked change in most people's awareness of the problems facing the mentally handicapped, especially through television programmes and films, the concern is usually a distant one. Only when a site for a hostel or home is proposed in their own locality are true feelings revealed. The imagined dangers to their children and the loss of value of their property set the pattern of most people's priorities. There is still a long way to go in terms of a true awakening of personal concern and understanding beyond the confines of those living and working

with these relatives and friends of ours.

I daresay that most of you who have had dealings with parents of mentally handicapped children are well aware of the difficulties which they face and the effect which these can have on families. There can be no harm, however, in reminding you that life is never normal. The strains and pressures are always there and, especially if there are other children at critical stages in their development, crises can be regular and damaging.

It is common for one or other parent to resent the degree of attention bestowed on the handicapped child and the weariness which results from sleepless nights and constant day-time vigilance. It requires little imagination to sense the effect on the family of the child who has no way of expressing itself bar screaming - and little imagination to sense the frustrations which the child itself will feel. Such situations are self-generating disasters and the pressures can all-too-readily result in break-up.

The pressures are one thing; the limiting effects are another. Baby-sitters are not easily come-by for hyperactive or fragile children subject to fits and other disturbing problems, although the professional foster-parent schemes are helping this, where they exist. Holidays, weekends away, or even nights out are very difficult to arrange and yet are as much needed as in any family. Short-stay care facilities are improving things but, as yet, are nowhere near sufficient to satisfy 'on demand' calls at any time, which is the only really satisfactory answer.

The range of possibilities for work is often controlled by the location of appropriate and acceptable services - I know that this has been so in my own case.

Yet, somehow, there seems to be among us parents an inbuilt desire to keep such general troubles to ourselves as far as possible and to present a calm and normal face to the world. Only when the breaking point is near and our defences are down will anyone beyond the immediate family discover just what is happening. We do not easily communicate our heartache, our anxieties and our weaknesses to the world.

There was some debate between my wife and me as to whether my main task today should be to talk about ways of communicating with a handicapped person in the family or to deal with the wide issues of communication between parents and those who are, or who should be, providing advice and support.

I have opted for the latter for two reasons. The first is that is a particular hobby-horse of mine and an opportunity to get the message across is not to be missed. The second is that the problems of communicating with a handicapped person will be specific to the individual and, although of interest as a study in depth, will not have the general application which is more

appropriate to gatherings of this kind. In any case, my wife and I have lived with the problem, not researched it, and my thinking about it suggests that we could itemise the difficulties but not readily identify solutions.

I know one thing, however, and that is that our daughter has developed methods of getting her own way which suggest that she is aware of more than she is able, or willing, to reveal.

And I know another. A mother can have a greater intuitive sense of what is wrong, or what is needed, or what should be done, than the majority of professionals are prepared to admit.

Most parents of handicapped children could readily present a case history and catalogue the failures in communication which have occurred through it. Some would be very funny; some very sad. It seems to me that there are certain crucial events, certain stages if you like, which case histories of this kind will have in common and I have given each of them a title in the hope that this may help to fix the event in the time scale and identify the people who were, or who should have been involved. The titles are:-

1 Becoming aware of something amiss

2 Sharing the initial concern

3 Facing reality

4 Crying for help

5 Finding a way into the system

6 Establishing a route through the jungle without a map

7 Hazards to be faced and overcome

8 Aids to navigation

9 Zones of darkness and light

10 'The Heavenly City'

1 Becoming Aware of Something Amiss

Who is the first to know? Or who is the first to notice?

In Christine's case, I now believe that the doctors must have known at the time of the birth, or very soon afterwards, that something was wrong or stood a good chance of being wrong later. But it took about three months and the initial signs of petit mal and the non-use of her right hand to suggest that all was not well. And it was we who noticed it.

2 Sharing the Initial Concern

The first point of contact, for my wife, was the Health Clinic. This led to the not-very-helpful response from the nurse 'You are making a lot of fuss about nothing. Christine is obviously going to be left-handed.'

It was some time before, through our G P, we obtained an appointment with a consultant paediatrician at the local hospital and, later, with a neurologist. We longed for some expert advice and help.

3 Facing Reality

The advice was pretty brutal and the 'help' merely the prescription of drugs.

'Christine will never be able to do things like play the piano. It might be best for you to accept now that she will be capable of very little and you should have another child so as to compensate. The phenobarbitone will help the petit mal.'

We were never advised as to what to do or who else to consult. We floundered around and although we had seen the specialists, the doctor, and the nurses at the Health Centre, we had no constructive advice as to what to do next. It was through contact with friends at the local Society that we found out about a private physiotherapist and a teacher for Christine.

4 Crying for Help

The first thing you come to realise, of course, is that, no matter how sympathetic other people may be, unless they have experienced a similar shock there is little or nothing that they can do.

We were lucky. We lived with my wife's mother and father and they were a wonderful support. They helped us in so many practical ways that we were able to cope. They were absolutely marvellous with Christine. Other parents were not so lucky. It is the loneliness of it all that can be so damaging. This is where the National Society, or MENCAP, is valuable. The local branch afforded us the first opportunity of meeting other people in a similar situation. Sharing a problem, and exchanging similar experiences, helps reduce the burden. You do not feel quite so odd; quite so alone; quite so guilty. And you feel you can have some influence, through the Society, for the good of the cause - improving facilities for the handicapped.

5 Finding a Way Into the System

In retrospect we see that there wasn't really a system. It was all very hit and miss.

I have already referred to the tests which resulted in Christine's being labelled 'ineducable' and this led, eventually, through the Medical Officer of the London Borough in which we lived, to Christine's attendance at a Junior Training Centre. The nearest at that time was some eight miles away and involved her leaving home at seven thirty to catch a coach and her returning at five. A long day for Christine but, at least, some relief for my wife. Before we had any sort of contact with the Local Authority we had tried the Spastics Society (Christine failed their tests too and was thought to be too difficult for them), a wonderful Danish physiotherapist and a Rudolf Steiner teacher. The last two were a marvellous help.

The snag is, I believe that there is still not much of a system. Mandatory education obviously helps to some extent but some twenty years after our own experiences there are still many problems to be faced and struggled with alone.

The basic difficulty is that responsibility for the mentally handicapped is shared, or split, between two authorities:

(a) the Local Government authority responsible for Education and Social Services; and

(b) the Health Authority.

The direction you take can often be determined quite arbitrarily by your first point of contact. If it is via your GP, then you stand a good chance of being 'Health' orientated; if it is via your Social Worker you could end up with Social Services. I know this may be an over-simplification but it has a large element of truth in it.

Perhaps things are getting better in some areas. One has to hope so. Health and Social Services should be talking to one another through Joint Planning Teams (or whatever) but the recent reorganisation of the Health Service is likely to take a little time to settle down and, in the meantime, in the County at least, a wonderful opportunity has been lost.

Four years or so ago Health, Social Services and Education got together to plan a Children's Centre which would include joint assessment facilities with all specialists working as a multi-disciplinary team. This would have provided a County-known first point of contact for any parent suspecting a problem or having been advised of the possibility of one at the time of birth. Doctors, Nurses, Teachers, Educational Psychologists, Physiotherapists, Speech Therapists, etc, etc would have been working together and, with the parents, helped discover and determine the best course of action for the child at all stages.

Because of reorganisation this project will not now go ahead. Thus further generations of parents have lost the chance of the single point of reference from which all should spring. Anxieties and frustrations will continue. And the doctor (Maureen Hodgson) whose brainchild it was, and who is with us on this conference, must be very sad - as we are.

6 Establishing a Route Through the Jungle Without a Map

It is a jungle and there are no maps; so what do you do?

First of all you have to rely on instincts. You must feel that there is a point to be reached beyond the jungle. The ultimate objective may change as you travel but it has to be there to enable you to carry on. Often the objective will reduce in brightness as you go. You will start off with a vision of recovery, then of achievement of maximum potential, and end up with hopes for nothing more than a peaceful, uneventful and, perhaps, happy existence for your child.

Secondly you need guides to help you on your way and intermediate landmarks to be reached where you can gain some refreshment.

We remember a particularly distressing landmark and a guide who came with a light to help us through the darkness. The moment when we had to accept that Christine needed to go into hospital at Harperbury (in Hertfordshire) and Dr Ricks who used to have regular meetings there with a group of us parents, gave us the first opportunity of talking over our anxieties and hopes, listened to us with sympathy and understanding and encouraged us to feel that we were as important to him as he was to us.

But the point of the heading remains - life with a handicapped child should not be a jungle and there should be maps.

7 Hazards to be Faced and Overcome

There is often a peculiar reluctance on the part of the authorities to issue information or to let parents know when services are planned or when changes are proposed. Even when such proposals are of obvious benefit and likely to be most welcome and reassuring, parents and relatives are often the last to know.

Maybe this has its origins in history - in the past, particularly in the case of hospitals, relatives and friends were few and far between and often difficult to trace. In the future, if proper relationships are to be established and maintained, those concerned will need to learn to spread their news more generously.

It may be a little difficult for those involved in this work

to appreciate and accept my next point, and it could be that things are getting better, but there has always been some slight sense of facilities being provided as a privilege and not a right. If ever this is felt is can lead to difficulties. Parents may believe it impossible to criticize for fear of some form of 'reprisal' or the possible removal of the service.

It is amazing how the threat of the 'Subnormality Hospital' is still prevalent among Social Services' and other Community-based establishments. It is amazing how regimes and incidents in wards may be accepted without comment.

What do you do when you believe that your child is being assaulted and your tentative enquiries are passed off with a shrug and the comment 'He tripped'? How can you get through to people directly involved if you cannot rely on their being truthful? This is a real problem of communication!

How can you get across the message, after long years of experience, that, if your child is having a particularly bad period of disturbance, it could well be due to a physical disorder or genuine illness?

8 Aids to Navigation

I have already mentioned one significant landmark in our life with Christine and someone who came forward to meet us and guide us on our way.

There can be no greater aid to navigation than the establishment of mutual trust and understanding. And it is impossible to establish such trust and understanding without the mutual acceptance of the important part which <u>everyone</u> has to play.

Life is not a matter of individual endeavour. It is a social activity and relies for its success upon our inter-dependence.

In the field of mental handicap we must be prepared to talk to each other, to listen to each other, to break down barriers, avoid taking up entrenched positions, be unafraid, be sensitive and remember that we are not concerned for ourselves but for those who cannot cope themselves and so rely on us for help.

9 Zones of Darkness and Light

Life with a handicapped person is different only in degree from that with anyone else. There are greater extremes of anxiety and joy, perhaps, and there is, of course, the underlying feeling that you are living on the edge of a volcano which is likely to erupt at any moment. To take the metaphor further, as a caring parent you cannot move house away from the volcano. It

is always there. Severely mentally handicapped children do not grow up and become independent; we grow older and still have a deep involvement with them.

Our own story has, overall, some periods of extreme darkness and others of considerable light. One of the light patches is Villa Eleven in Turner Village. Of course, even this has dark patches: anxieties over drugs; periods of agitation and disturbance for Christine, which will always be there. But marvellous staff; relationships built up over the years with Sister, with the nurses and with all the other residents in the Villa. Dr McKibben and the other doctors; the Unit nursing officers; and the administrators. And we meet other parents on the Unit and try to do things together to help the residents and each other.

And after twenty eight years, last month my wife and I attended our first case conference about Christine with Dr McKibben and members of the hospital staff. Joy!

10 'The Heavenly City'

We shall have reached this when everyone is sitting down together asking each other the question, 'Is this all right for you?' and when everyone, including John and Jane, is able to say 'Yes' or just not or smile in accord.

At each point along the way there was the need to communicate with others. Sometimes it was easy, sometimes it was decidedly difficult, sometimes it was impossible to identify anyone to communicate with. The reasons for the communication varied. Initially it was to obtain information; then it was to share experience so as not to feel alone; then to seek guidance as to what to do. There was usually some sought-for expertise in others which, it was felt, would reveal all and resolve difficulties. Rarely would it be acknowledged that one's expertise, purely and simply as a parent, might be helpful in a particular situation.

Yet in terms of 'knowing' John or Jane (or in our case Christine) parents are probably in as good a position as anyone to express an opinion. It is just that 'undue possessiveness', 'unreasonable sensitivity' and 'fussiness' are labels which can too easily be applied to us by professional experts wishing to dismiss an irritating additional factor in a problem.

We all know that there are failures in communication in ordinary life at every moment of every day. Sometimes they arise merely through lack of thought - 'It didn't occur to me to tell you.' Sometimes they are deliberate - it is easier not to say anything than to cause trouble or to raise doubts in people's minds. Sometimes they arise through shyness and the feeling that what you have to say cannot be of any significance. Sometimes

they are the result of fear and anxiety and dread of imagined consequences. The effects are usually surprisingly similar - wrong impressions, misunderstandings, distress and erroneous decisions.

Communication has only taken place when the person receiving the message has fully understood it and shows that this is so to its originator.

The over-riding difficulty these days is TIME. It takes time to listen and to make sure that you have understood. I clearly remember, on one of my Development Team visits, a nurse saying to me, 'Of course I should love to talk with parents when they come on to the ward but I know that, if I do, it will involve not only the time spent in talking but also the time required to take action on what they say. It is easier to be doing something else.'

As a parent I suppose my answer to this is to quote the inevitable 'A stitch in time saves nine'. Everyone could save themselves an awful lot of trouble, and save us an awful lot of anxiety, if they changed their attitude. But then, I'm prejudiced.

So - How do I Summarise?

Problems arising from lack of communication between professional advisers and parents are legion but seem, to most parents to be known only to themselves and not to the doctors, nurses, teachers and administrators who generate them. Failure to communicate may be due to ignorance, thoughtlessness, insensitivity, fear or, simply the desire for a quiet life. But the results are usually the same whatever the cause - anxiety, misunderstanding and hurt for the parents and lack of information and help for the professionals.

There can often be direct communication between the handicapped person and the relatives, where it is impossible with other people. A mother's sensitivity to her child's needs can illustrate this. It should be acknowledged that parents have an important part to play as qualified members of the 'caring team' and can be a positive help and not the irritant and hindrance which they are often thought to be by others.

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Before coming to Essex in 1972 he was a partner of Design Research Unit in London, a practice of Architects, Industrial

Designers and Graphic Artists. He was a member of the DHSS multi-disciplinary team concerned with a Pilot Project in Sheffield setting up a full service and a proper range of facilities as suggested by the Government White Paper 'Better Services for the Mentally Handicapped'.

He was subsequently commissioned by the DHSS to do a follow-up study and report on the buildings in Sheffield which resulted from the Pilot Project. He also carried out a national survey of Local Government provision for Mentally Handicapped, evaluating buildings in use.

He has undertaken study tours in Denmark and Sweden visiting facilities for the Mentally Handicapped in those countries.

He is now on the panel of parents attached to the DHSS National Development Team for the Mentally Handicapped, a role designed to ensure that the 'consumer's view' of the services is available to the Team.

A PARENT'S STORY

MAURICE COLLINS (Parent)

Transcription by JOAN INGLE (Turner Village Hospital)

The reason I am speaking to you is because I have a handicapped daughter who's twenty-one. Her name is Kim and interestingly enough quite a few of the professionals who have been involved with her over her past are here in this room, which means that the best people come to these conferences. I have got my kid into the best type of care! This chuffs me no end. Bill Apps, this morning, took an approach which was very much based upon his individual view and how he has seen the services as they react to him. The thing I would like to put over is how I've existed within two different types of organisation - one a self-help group, KITH & KIDS, and the other a voluntary association, MENCAP, and how these relate to the general services that are provided.

When Kim was quite young, she was six or seven, I met by chance another family who had two partially sighted boys and, to cut a long story short, we started a group of parents who used to meet together because we felt a terrible isolation. Now, as time developed, we learnt very rapidly that we shared a whole range of experiences, a whole range of knowledge. We never really identified ourselves as a self-help group, but we supported each other within the group. We weren't at that time interested in teaching anybody else any lessons. All we did was to get the best for anybody who belonged to the group. And anybody could join. It didn't matter what age the kid was, nor where the parent came from - they could join. The actual aim of the group was to find solutions for us as families and our kids. Unlike Bill, who was trying to explain his own isolation, we found that the minute you share your own situation all sorts of things begin to happen. You begin to realize that you have power because instead of you, many other parents are speaking for your child - twenty or thirty parents. And it's terribly important to be able to stand back from a situation and have other people fight for your child. We found that to deal with professionals, and many of them are not particularly good at their jobs anyway, we needed to use all types of ways to get solutions and to initiate action. It wasn't just being nice to people. Sometimes it was actually putting on 'pretend' situations. Parents were taught to break down in front of Social Workers. We taught them how to exaggerate a crisis - 'My husband's leaving me.' - 'My husband's trying to kill me.' - 'I'm going to kill myself.' This gets action, and how! Things aren't easy, and I think it's a sad reflection that parents have to stoop to this kind of thing to

get action. Because, as far as we are concerned, our own children should have the best type of service that exists.

So KITH & KIDS developed a whole lot of ways to get this action. One thing that happened, and I always quote from our very early years, was where one family in our group, with a very severely handicapped spastic daughter, had been asking the local Social Services Department for a waterproof mattress. I beg your pardon, not waterproof, one that was uneatable - because the child ate a mattress. This had gone on for two and a half years. By chance, a programme of Radio London gave two hours' radio time to any local organisation. We were lucky enough to get in, but before we went on this programme we sent a letter to the Head of Social Services, (I won't name the Borough, but it happened to be Haringey) telling him we would be on the programme and we would mention that Clare had been waiting for a special mattress for two and a half years. Would he be prepared to phone in (it was a phone-in programme) to explain why she hadn't had it. We weren't making difficulties, we said. We were very nice about it. The programme was on the Wednesday night and the mattress turned up on the Tuesday night; and we thought 'bloody marvellous!' How easy it is to get things moving. Be nice about it, but have the implied threat. I think these lessons began to translate into a whole range of actions.

On driving down in the car with Eddie, whose family started KITH & KIDS with me, we were discussing a problem of a child whose family is in our group. They live in Islington (I know there are people from Islington here) with three autistic children - three - and man they're heavy! I find it difficult to be with one of these children for five minutes. I won't go into how Islington treated them in their early years, which was totally abhorrent and unbelievable, but now, in fairness, they're reacting in a positive way and things are happening. Two of the children are away at St Christopher's in the North and the third, Marcia, is at home. Now she is a very difficult child, and a new situation arose at the local school. All of a sudden the father phoned us up and said 'They've kicked her out. They kicked her out because she is so handicapped!' I said 'How can they kick her out of a handicapped school if she is so handicapped?' 'Well they've kicked her out - they've suspended her. I believe headmasters can do that.' They can suspend children for no reason, or because they can't cope, yet they assume a family with two other autistic kids, just as difficult, can cope at home. Right, she went home.

Vic, her father, who's a very nice guy, (I mean he's the only person, in my estimation, I could make into a saint - he's the only person I know. He deals with these kids incredibly well) said 'What am I going to do? What am I going to do?' So we had to do something. KITH & KIDS tried to react in a way that would bring a response. This we did by pretending we were the Guardian Newspaper, and that we had heard that this kid had been kicked out of school. We had a telephone number for them to ring back. We said 'This looks a fantastic story - kick out a kid

from school, a severely handicapped kid whose parents live in poor conditions, a family with two other autistic kids. There's a good story in this, can we come down and interview the head?' Ten minutes later (and the school knew it was KITH & KIDS who had contacted the paper because the person who pretended to be the reporter had said this information had come from KITH & KIDS) one of the parents got a phone call saying 'Please, we'll sort out the difficulty. The only problem is that there is a heater on the wall of the toilet, and we were scared that Marcia would pull the heater down off the wall and get an electric shock. That's the reason why we sent her home.' Anyway, to cut a long story short, they asked us to hold up the article, and to stop the Guardian coming down. We said 'OK fine, we'll do that,' and sure enough things began to happen. But they conned us because she was supposed to go back to school the following week and she didn't get back until the following term. Now the illustration I've tried to make is that within a self-help group there is opportunity to learn a whole range of ways to deal with professionals, since in the main they are bad. I only wish that I could say that they are super teachers, super social workers, great adult training centre managers, but in the main they are not good. I know that most of you are professionals, but I have to say that those who attend conferences are the good ones. But we never see them because they are always at conferences!

If I can go on to tell you about some of the other things that we have also discovered. As we are talking about communications, the theme of this conference, one fascinating thing happens within our self-help group after one of us attends a case conference. We discuss how you relate to us within that situation. A lovely thing happened. A family in Islington with two handicapped children, both very young, went to a case conference at the Charing Cross Hospital. As it happens there they are super. (The beauty of KITH & KIDS is that we make recommendations. That's why Peter Turner has so many of our kids. That's why his empire extends beyond his parish - because the name gets around. My daughter went to Peter's school, and quite a few KITH & KIDS have gone there as well). Anyway they went there, and they sat in on this case conference, and they said to the doctor in charge, 'We don't think we'll understand what you are going to say, so can we record it?' To our astonishment he said 'Yes', and this recording was brought back to KITH & KIDS. At our next meeting we listened to the recording; and it was amazing, because none of us understood it. We played it four times, but it was all in the jargon of the professional which gives them that mystique which we are never able to penetrate. And yet, why don't they use the good naval words available for most situations? From our point of view as parents, the self-help group gives us the ability to stand back and then return to the professionals and say, 'Look we didn't understand it - not one of us at this case conference, nor could any of the twenty eight of us in our group understand it. So please could you explain, point by point, what you were talking about?'

Now, one thing that has been recognised a long time in KITH & KIDS, is that not only are there good professionals, but there are bad professionals; and there are great ways of doing things but also ways not to do them. We wanted to make our kids more socially able. I was complimented because Malcolm Jones, before this meeting, said to me 'I've met you once before haven't I?' and I said 'Yes'. He said 'I came down to your "TWO-TO-ONE" project and I took away lots of ideas with me.' He said that to me ten minutes ago and I really felt chuffed. To think that a guy who is doing such a fantastic job, had actually said that he had learnt something of a professional nature from a group of parents who were trying to solve the problem of what to do in their holidays! Holidays for us are a fantastic ten weeks without these kids at home. We've got our normal kids and we've got our handicapped kids - sometimes two or more handicapped kids. What do you do with them in holidays? We developed a scheme, and this is going back a bit. In fact our ninth event is coming up this year. It is called a 'TWO-TO-ONE' project, because we are a group that believes in integration through using two volunteers to work with one handicapped child in a highly structured social training project, but under the supervision of professionals. We bring in a couple of psychologists and we pay them (so we are the governors!) - about £150 - no tax but cash and no questions asked. A lovely way of actually getting things moving! So we got good professionals. Our kids were assessed as we wanted them assessed. We did the assessment in fact. After our third year around, we actually began assessing our own children! Interestingly enough, very rarely do professionals say to parents, 'You should assess your own kids' but when you do it, you recognise all the problems in a logical way that you can understand.

I can remember with my own daughter when she did not wash her hands my wife and I argued as to whether she could or could not. I said 'Yes' because I'm an optimist, she said 'No' because she's a pessimist. Well she couldn't wash her hands. We tried for twelve days, actually saying, 'Kim go and wash your hands' and she didn't wash her hands. Indeed, she couldn't at that stage. But it was very interesting that we had carried out our own assessment. We had developed a system for building a programme. Every kid should have this kind of programme, and a timetable helps. I was watching Malcolm Jones' timetable - it was super. We developed a highly structured programme that was implemented by untrained young people between the ages of eighteen and twenty two. They would actually work with our kids in a very intensive way for a whole fortnight. It was fantastic. The kids loved it. The volunteers loved it. The parents loved it. Everything was superb, and since then we have kept on doing it for the last nine years. Now we've introduced a full time residential situation, where kids live in with young volunteers who, without professional help, develop programmes to use in these ordinary houses for a fortnight. The kids live in the community with other young people. It always astonished me (and it always will) that we assume that mentally handicapped people always want to live together. I find it difficult to live with a

mentally handicapped person, why the hell don't they? And we have all this talk about units being developed to put the mentally handicapped all together as they've done in Cardiff. What you do is to create integrated living situations where students live with handicapped people. In KITH & KIDS we would like eventually to set up that type of residential situation permanently. So our 'TWO-TO-ONE' policy project from our point of view was superb. A lot came out of it and it runs now in the winter as well.

Another development was that volunteers listened to us when we were speaking about Harperbury in front of a group of our kids. One of them (in fact the same one that ate the mattresses) had gone to Harperbury, where there is a superb doctor. The interesting thing about KITH & KIDS is that you get to know the professional who's good. And you recommend him - and Dr Ricks at Harperbury is a parents' man. (It was very interesting to hear what Bill Appe had to say about Ricks because we have all had that experience with this superb man.) This kid was going down on the last day of the 'TWO-TO-ONE' and the volunteer said 'No way will I miss my day of the 'TWO-TO-ONE'. No bloody fear. I'll go down and I'll carry on my 'TWO-TO-ONE' at Harperbury.' And he went down, and he was appalled by what he saw. He went back and said, 'I'll put on a 'TWO-TO-ONE' at Christmas.' Now this was different from us, the parents, doing it. This was a volunteer at Harperbury. 'I'll put on a 'TWO-TO-ONE' and he did in fact do a 'TWO-TO-ONE' in one of the units at Harperbury and it was published by MENCAP and called Take Six Children. Because the psychologist at Harperbury had fifteen hundred people to deal with, she couldn't provide the individual programmes they needed. But we hired people to go into Harperbury and actually assess people.

I always remember one particular guy who went there. He was a professional who went and visited - a professional who was involved with us. He said that for the first time he was in tears, because the problem was so big and communication was so bad and he couldn't help. He felt that he was a total failure. I had the same experience. I went down one morning, because the volunteers were crying out for people to come down and show them the way, and I always remember the thing that struck me most was that they got the kids up at seven in the morning. The idea was that there should be an hour of social training in terms of dressing. I went there and I was sitting beside a guy who was an engineering student. As I watched him I saw that he was putting wires into socks and into the arms of jackets and I said, 'What did you do that for?' He said 'The first problem I noticed when I came in is that these children cannot locate where they should put their feet and their arms. The kids can't locate, so how can we make them locate? The easiest thing is to start at the end and work forwards. We'll put a bit of wire into the sock, so they don't have to start to open them and so on.' Now I don't know if that's a reverse sequence in terms of training people, but that's a bloody good idea. Here was a solution that immediately helped the kids to get moving. And these young

untrained people, coming out of all sorts of disciplines, aged between eighteen and twenty, had developed the idea. And they developed a whole load of new ideas within that setting. And this project went on, and they lived and worked within the hospital. Now as far as I know it's never happened again, but that type of concept, and that type of volunteer, made us bring together a group of people to provide a back-up service for KITH & KIDS. This group has been with us now for six or seven years. It is a volunteer group - totally volunteer - and they support us.

They run Sunday fun days, (there's one in two weeks' time) where they have a project. We, as parents, take our kids there and then we all go out to dinner. By now we know every restaurant in London, because we go out to dinner when the kids stay there and cook their own meal. Last week they went bowling - a load of kids and volunteers. However severe their handicap - this doesn't matter in a bowling situation - all the kids and volunteers bowl. We are not talking about a few volunteers and handicapped kids, but up to fifty of them go. They went to a night club a few weeks ago, but unfortunately one of the kids broke up a table and he had to be removed. In general this does not happen. They go to pubs. We have one very severely handicapped girl in the group, who has gargoylism and is in a wheelchair, whose favourite expression is 'a pint of bitter please'. One of the volunteers taught her to say that. She loves pubs. Most of our kids don't get the opportunity of going into pubs with a group of young people of their own age. Two years ago, this girl was kicked out of a pub in the East End because she looked handicapped and the publican wouldn't let her in. The volunteers kept on going back in with the kids, each time with more, because you know we've got hundreds of troops. They didn't buy a drink but just kept going back in with more and more of the kids. Eventually the story goes the publican said, 'OK, OK, OK; it's OK, you can come in.' 'Piss off, we'll go somewhere else' they said. The difference is, that in utilising young people in that way, you are creating a situation whereby they are living a normal type of life. I mean, I go round petrified about what's going to happen - they are going to run in the road; they are going to knock down an old lady; but these youngsters do not have the same problem. They relate to these handicapped people in a fantastic and wonderful way.

We should utilise them more and more. But we are beginning to develop this angle much more since our experience has been so good. Because they are volunteers we have our problems as everyone else has who depends on volunteers. Sometimes they don't turn up, and sometimes they do. We have baby-sitting volunteers and the beautiful thing about it is the fact that the brothers and sisters of the handicapped kids started it. Two handicapped children, both partially sighted, started it; and they hold the whole situation together now. That is something I would like to see developing further and in fact I do everything I can to encourage it.

I'm MENCAP chairman for my region, and one of the things I always try to do, is pass on the lessons we have learned, working with other families. Look at the problem overall how we get enthusiastic young people involved with our kids. Kennedy said a long time ago 'In future, people will be tested not on what they know, but on what they can communicate to others.' Our kids fall into that category beautifully, so we should really work on that.

I have spoken a great deal now about the 'TWO-TO-ONE'. Now we actually have a co-ordinator. Many years ago we set up NETWORK, which is a legal advice centre for disabled people and their parents. It has been running for years, involving barristers, solicitors and parents. They have developed a method of aggressive legal responses - creative legal advice perhaps I should call it. If there is a problem, they put their name to it, and the beauty is that all local authorities respond to a letter from a solicitor or barrister. And we use it. When we first started, we had one particular barrister who always said 'If it stays still, paint it, if it moves, sue it.'

This way of using the law fascinated me. Social Services had always told us that although they often provided day care, they were not forced to do so by law. I thought somehow that can't be so. These buggers don't do that type of thing for nothing, so there must be a reason why. And after a lot of research, and nobody could help me - including the DHSS in London - I got the answer in a book for social workers which I picked up at Foyle's. I noticed it kept on talking about a circular dated sometime in 1974. Nobody had this circular except the Welsh Office, and they sent me a copy. There engraved in this circular - yes, you have to provide day care if there is somebody who requires it - EUREKA!

We phoned it straight down to MENCAP. We've got a guy in Parliament, a MENCAP guy, who sits there all the time. I said, 'Rolf, look what we've got. We've found this proof you see.' He said 'Oh, no you can't be right.' We sent a letter to the DHSS with the copy. We said, 'Does this mean that you have to provide adult training centres?' 'Oh no, we don't have to provide adult training centres. It means there has to be some type of day care.' That was really what we wanted. We had made mistakes but now we had the answer we needed. In that letter that came back, and they didn't really waffle about, they had said, 'No' to adult training centres, but they had said 'Yes' to day care. So all of a sudden we had a real base to work on. I say this because it's amazing how important the law is in terms of what we achieve. When we wanted teachers involved until our kids were nineteen, since it was in the Education Act, how often local education authorities did not accept it! To teach our kids up to nineteen we had to invoke the law of the land. Funnily enough yesterday at the annual general meeting of MENCAP we found clear evidence that a parent can take a local authority to court. He does not have to go to the Secretary of State as everybody used to think. So you can see how important it is for parents to get together in self-help groups. It's essential for them to have objectives and

aims for their own kids even though they might not see the wider scene at first. Their own problems as they relate to their own kids drives them on and in improving their situation they improve things for everybody. How do we translate that kind of personal experience into a step forward for everyone? That is where MENCAP comes in. It is the most powerful political organisation in the country. It has four hundred and sixty branches, seventy thousand members, everyone of them a parent of a child, and therefore willing to give an awful lot. Never before has that force been harnessed, since never before did we manage to organise and really make things work in such a way that it could move mountains. Let's face it, what counts is political action that cons people into thinking that you are strong. In KITH & KIDS we always say that it isn't how strong you are, it's how strong they think you are. That's the difference.

The beauty of parents' organisations is that we are your ally. We're your only ally. We are the people who can say anything without calling down recrimination. They can't sack you, if we speak for you. There's a man not sitting more than one row from me, headmaster of a school (I won't mention his name, but we are always making jokes about him), who put a parent up to sue him so he could get another member of staff. Now that's what I call using your parent power to get things moving. In Haringey recently we had a problem. A general hospital called Bounds Spring is made up of four small units. The District Health Authority wanted to spend revenue money on this hospital, so there was pressure from all sides to get the use of it. 'How do we get that hospital?' we thought. We don't mind using a hospital for our purposes although we're against hospitals. This could give us four ideal units with twelve places in each, right in the middle of the community, for the severely handicapped, a service we do not have. The psychiatrist in charge of the health authority in that area called on the local MENCAP and said 'Look, we have got a problem and unless we create pressure, we may not get that place because everybody else is screaming for it.' We had a little meeting and set up a pressure group and we called it NETWORK, because all our other different hats were thrown into the ring in support. We ended up with a combine of twelve organisations including the local Catholic Church because somebody went there. We printed a heading, a very impressive letter heading, naming all these organisations and any others involved in providing care for the severely handicapped in the Borough of Haringey. We churned out letters to everyone, including the local authority. Then, to cut a long story short, we heard, only last week, that Bounds Springs is now going to be the residential care unit for the severely handicapped in the Borough of Haringey. Now we were only a part of it but what I am emphasising is that it is the joining between professionals and parents that gets results.

How does MENCAP relate to the general problem of handicap? Any overall national organisation like MENCAP has a duty to mobilise action at every level. It has a national duty to pressurise government and the DHSS. It has a regional duty to

look after counties such as Essex as well as London, and it has a local duty to individuals who are mentally handicapped.

One of the ways that we mobilise local response is to produce a paper, which some of you may have seen. It is called STAMMA which means 'Standards That Are MiniMally Acceptable.' Now you must believe that as parents the standards that are minimally acceptable to us are the best there are. We fool you lot because you think we mean minimal standards will do. But we don't! We mean the best that is possible. Over the last four years we have looked at adult training centres for the over nineteens and at education. Now we have updated our ideas and are ready to inform parents at local level what they should be fighting for since if the professionals think we don't know they'll keep us in the dark. We want programmes, like the ones Malcolm Jones was showing, yet when I went to one adult training centre and said 'What programmes do you have?' they showed me a timetable of daily events with six lines. When we asked 'What is an assessment?' we were told in twelve lines on a piece of paper. So we have to learn, since we are the people who need to know all that professionals do if we are ever going to improve what they are doing for our kids. So STAMMA is a way of imparting 'know-how' to local societies about how to set up a plan of action and how to get results. It is difficult because every aspect has to be covered including social services, hospitals, adult training centres and so on. Whatever has to be done, we do it. It was in this way that we managed to develop a sort of an awareness at local level that made professionals aware that parents knew what they had the right to expect. It's taken a long time. It's taken four years, but then all of a sudden people are beginning to realise the dam has burst. Yes, STAMMA has a lot of value, and there are some areas of the country that have achieved an enormous amount through it.

I will, if I can, end up with one or two of the things from my own experience that I feel are very valuable. In KITH & KIDS we started off believing totally in integration (which we still believe is one of the most important factors) but we have tried to do it gradually. As parents, we live in the community with our kids, so any kid at home is integrated anyway. So, we don't believe that integration can't happen or won't happen. We made it happen. We are there and our kids are with us, and that's lesson one. Secondly, we have realised, through 'TWO-TO-ONE', that young people in the community do react well to our kids, and they can become a special part of what we are doing. That's another very important thing.

Chris Kiernan, who spoke yesterday, is researching a project that stems straight out of our 'TWO-TO-ONE' experiences which led to adult education integration projects in two London boroughs. The basic idea in our philosophy is that if you can break down that barrier, and it is a tough barrier, integration follows. Although I believe in planning integration, you can't stick two mentally handicapped kids in a room with fifty other people and think that everything is integrated. It doesn't work like that.

But if each handicapped person is with somebody who is a friend to him and an advocate to help him the whole problem is solved, because both have accepted friendship. That is real pioneering. Both boroughs have taken these over as going concerns, and the ILEA is considering setting up a full time co-ordinator to develop these types of schemes. I would like to put to you that this concept of integration, which leads to the utilisation of the community and community facilities, and especially the utilisation of young people, is one of the most important ways to break down barriers. At Malcolm Jones' school fifty young people came in for ten hours each per week. We should do this kind of thing everywhere. Young people are needed in the hospital, especially the hospital, since if you can organise and develop situations where they can come in, in a structured way, and be with handicapped people, a lot of the problems that we all have experienced with hospitals will disappear.

Just let me draw together, if I can, the strands of things that I have been saying. Parents and professionals are allies. We are all allies. It is important that you use us and it is equally important that we use you. I'm very happy this morning, as in the quarter of an hour coffee break, three schemes have been set going simply because people have been speaking together - three schemes! That's very, very important. Secondly, in terms of the political situation, parents have not only to be active, but also strong and organised. They must know how to develop a strategy to effect change. That's what I think communication is all about. Strategies have to be thought through. The crying in front of the Social Services is just part of creating change and developing a whole campaign. It's all based on the same principle. I hope that, in the future, all of us can work together in a very structured and creative way, to effect the types of change that this conference has been all about.

APPENDIX 1
The Makaton Vocabulary

STAGE ONE

Mummy (Mother)
Daddy (Father)
Brother
Sister
Nurse
Doctor

Drink (Cup)
Biscuit
Dinner

Toilet
Bed
Chair
Table
House (Home)
Car (Bus)

I (Me)
You

Where?
What?
Here
There

To sleep (Bed)
To drink (Cup)
To eat (Food)
To look (See)
To stand-up
To sit
To wash
To bath
To go
To come
To give

Good (OK) (Hello)
Bad (Naughty)

Yes
No

Please (Thank you)

Good morning
Goodbye

STAGE TWO

Man
Lady
Boy
Girl
Baby (Doll)

Bread
Butter
Egg
Milk
Tea
Sugar
Cake
Jam
Ice-cream

Door
Window
Fire (Heating)
TV
Lamp (Light)
Telephone

Dog
Cat
Bird

Tree
Flower

Knife (Cut)
Fork
Spoon
Plate

Book
Teddy
Bricks
Ball

And

Hot
Cold

Clean
Dirty

STAGE THREE

Sweets
Cigarettes
Apple
Orange
Banana

Fish
Rabbit
Horse
Cow
Pig
Sheep
Butterfly

Boat
Train
Aeroplane
Bicycle

To have
To walk
To run
To kick
To dig
To ride (Horse)
To jump
To climb
To swim
To fall
To shave
To brush hair
To brush teeth

Big
Small

More

Up
Down

My (Mine)
Your (Yours)

Sorry

Now

STAGE FOUR

Teacher
Boss
Friend
Children

Name

School
Work
Outside
Cupboard

Pen (Pencil)
Paper
Scissors (Cut)
Picture
Sand
Water
Thread (String)
Paint
Key
Box

Toput
To make/do
To sew
To cook
To sing
To play
To know
To think
To work
To read
To write (Draw)
To paint
To teach
To build
To break

We (Us)
They (Them)

In
On
Under

STAGE FIVE

Priest
Milkman
Postman
Policeman
Fireman

Church
Shop
Road
Garden
Fire (Blaze)
Post-box

Money
Bag (Carry)
Letter (Stamp)
Time (Watch)

To carry
To throw
To catch
To stop
To help
To like
To want
To quarrel

Quick
Slow
Happy (Pleased)
Sad (Miserable)
Difficult (Hard)
Easy (Soft)

Strong
Heavy
Clever
Angry
Frightened

To be patient
Mistake
Trouble (Matter)

But

STAGE SIX

Country
Town
Sea
Cinema

Holiday

Colour
Red
Blue
Green (Grass)
Yellow
Black
White
Brown
Orange

To begin
To finish
To bring
To ask
To speak
To listen
To be able (can)
To forget
To grow

Same
Different

New
Old

Beautiful
Smart
Nice
Kind

Ours
Theirs

Another

With

Who?
Which?

STAGE SEVEN

Numbers 1-10

How much?
How many?
How old?

Many (A lot)
Some (Few)

Time (Hour)
To-day
To-morrow
Yesterday
Next week
Next year
Last week
Last year
Long time ago
Saturday
Sunday
Night
Day

When?

Always
Again
Late
Early

Before
After

Wages

To buy
To save

Sun
Rain
Wind
Snow
Stars
Moon
Sky

Careful
Expensive (Pain)

STAGE EIGHT

To choose
To win
To dance
To find
To understand
To remember

Birthday
Christmas

Party
Parcel
Balloons
Photograph
Camera
Mirror
Radio
Newspaper

Sandwich
Beer
Sausages
Meat
Potato
Bacon
Cheese
Coffee
Tomato

First
Last
Next

Over
Through
Near (Close)
Between

Lucky
Hungry
Thirsty
Worried

Really (True)

Why?
Because

STAGE NINE: ADDITIONAL VOCABULARY

Handicap
Deaf
Dumb
Blind

Specific
Medicine
Tablet
Injection
Operation
Sick
Ill
Pain
Dead
Hearing aid
Spectacles
Wheelchair
How are you?

People
Soldier
Sailor
King
Queen
Farmer
People
God (suggest, sign Jesus)

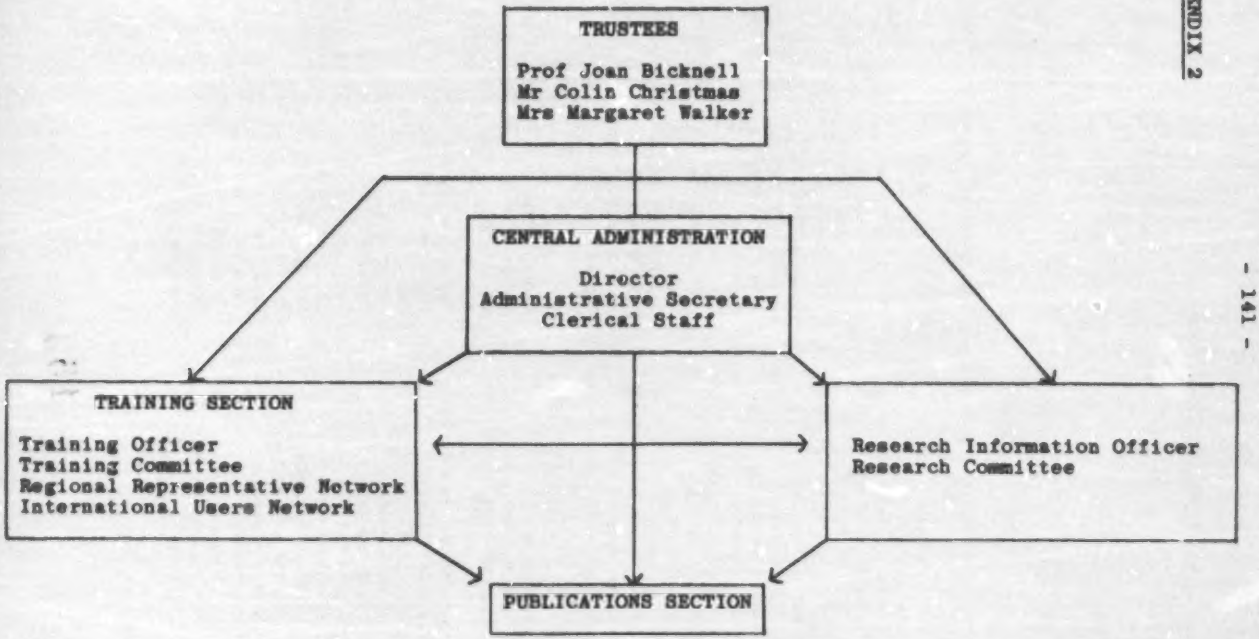
Clothing
Mimed

Parts of the Body
Mimed

Names:
For family or close acquaintance, often the initial letter of the name is finger spelt, or some noticeable feature, eg little boy - spectacles is signed.

Rooms:
No specific signs for rooms, eg classroom, bathroom, but the deaf sign the verb eg to bath conveys bathroom, to cook conveys kitchen, for classroom suggest school.

CURRENT MAKATON VOCABULARY DEVELOPMENT PROJECT ORGANISATION



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